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## ABSTRACT

Designed to celebrate family/interprofessional collaborative partnerships, this publication describes high-quality examples of how families and professionals at the family, community, state, and national levels have worked together to create programs and practices that are family-friendly and responsive to what families have said they want and need. Following the preface offering a call to action, the publication's contents are: (1) "Creating the Context: Family-Centered, Community-Based, Culturally Sensitive Partnerships" (Kathleen Kirk Bishop and Polly Arango); (2) "The Gallivan-Hackett-Waters Story: Three Generations of Partnerships" (Pat Hackett-Waters, Glen Gallivan, and Lucille Hackett); (3) "Family Voices: A Grassroots Public/Private Partnership" (Polly Arango, Betsy Anderson, Julie Beckett, Josie Woll, Trish Thomas, Maggie Schwarz, and Bob Craig); (4) "Peanut Butter & Jelly: A Culturally Sensitive, Community-Based Family Center in New Mexico" (Sylvia Ruiz, Antionette Tellez-Humble, Maida Trujillo, Stella Primavera-Stanz, Troy Martinez, and Debbie Sanchez); (5) "PACER's Team Training on Transition: A Statewide Partnership with Youth in Minnesota" (Ceci Shapland and Corey Jackson); (6) "Project Unity: Family Empowerment and Community Renewal in Texas" (Jeannie Heller and Jaslin Evette Smith); (7) "Applying Lessons Learned: Family-Centered, Interprofessional Education and Practice" (Bonnie Strickland); and (8) "Responses and Recommendations ('Recommendations for Practice' by Mary Skidmore Taylor; 'Family Response' by Betsy Anderson; 'Social Work Response' by Paula Allen-Mears; 'Health Response' by Tom Tonniges and Dianne Haas; and 'Education Response' by Dean Corrigan)." The publication's appendix lists suggested readings and references; describes the National Commission on Leadership in Interprofessional Education; and lists principles of family/professional collaboration, key elements of family-centered care, fundamentals of cultural competence, and Board members of Project Unity. (EV)

# PARTNERSHIPS AT WORK

**Lessons learned from programs and practices  
of families, professionals and communities**



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# PARTNERSHIPS AT WORK

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and practices of families,  
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## **DEDICATION**

Every day, in communities across this country, families and professionals use their unique and complementary skills to weave wonderful partnerships that protect, nurture and support America's families in their most important job – raising their children. We take on this task and create these mutually satisfying partnerships out of love and devotion to the next generation. This book is dedicated, therefore, to the children and youth who will carry our hopes and dreams into the 21st century.

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## Acknowledgements

This publication celebrates family/interprofessional collaborative partnerships. It describes high quality examples of how families and professionals at the family, community, state and national levels have worked together to create programs and practices that are family-friendly and responsive to what families have said they want and need. It is a continuation of our original work on collaboration, *Family/Professional Collaboration for Children with Special Health Care Needs and Their Families*, K. K. Bishop, J. Woll & P. Arango (1993), and has contributed to a fuller understanding of the definitions of terms like family/professional, family/interprofessional, collaboration and partnership and of the distinctions among them.

This publication was created with the enthusiasm, support and commitment of *Merle McPherson*, Director, and *Bonnie Strickland*, Senior Public Health Analyst, Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau. They launched the initiative on interprofessional education and practice and have continuously modeled family/interprofessional collaborative partnerships.

The names of our writing partners are found in the Table of Contents and at the beginning of each chapter. All of our partners cooperated with our endless requests for more information and were patient with our unlimited telephone messages, e-mails and faxes.

The members of the *National Commission on Leadership in Interprofessional Education* contributed some of the ideas for the featured programs and practices. *Dean Corrigan*, Education Co-Chair, was unfailing in his review, encouragement and support. *Roy Edelfelt* met with us on several occasions and assisted us with the initial direction of the publication.

Many, many family members and professionals, too numerous to list, influenced our thinking and contributed their ideas to this publication.

Our collaborators in the other two MCH-funded interprofessional projects, the **Health and Education Collaboration Project** in Hawaii, and the **Higher Education Curricula for Integrated Services Providers Project** at Western Oregon State College, suggested some new ideas about interprofessional partnerships which also contributed to our thinking.

The **Partnerships For Change** staff has played numerous roles in seeing this publication through to completion with unwavering energy and commitment. *Cathy Crow*, Family Consultant, inspires us and urges us on by sharing her ideas and experiences as the parent of *Nick*, a teenager who has many talents and special health needs. *Peggy Weaver*, Project Coordinator, keeps us organized and facing forward, despite all the large and small details of putting together this publication. Her special contributions include painstaking review, telephone interviews with our partners, and discussion of language and ideas. *Barbara Flaherty*, former graduate social work assistant, developed the list of support materials contained in the references section. We couldn't survive without the services of our project assistant, *Maureen Charron*. Maureen is unfailingly cheerful and encouraging, as she unglitches our computers, makes endless telephone calls, and creates graphics and charts from our unfinished ideas. *Marilyn Eick* joined us toward the end of this project, and provided invaluable editorial assistance.

The collaborative thinking and writing that went into the creation of this publication was one of the most challenging aspects of our work. We struggled with concepts, language, and expression of ideas. It took much more time, energy, commitment and discussion than we could have anticipated. We believe the finished product is much richer as a result of our collaboration with our many thinking, writing, reading and listening partners. We thank all of you for your very valuable contributions, and for staying with us to the end.

Kathleen Kirk Bishop    Mary Skidmore Taylor    Polly Arango

# Preface



## A Call to Action

by Merle McPherson, MD, MPH

It is a special pleasure for me to contribute the preface to this book. For family and professional partners, this publication is another step in our pursuit of learning how to develop services and programs that are responsive to the needs of children and families.

The pursuit of high quality, family-responsive services is part of the progressive and proud history of the Maternal and Child Health Bureau (MCHB) and its concern for the health of children and families. My involvement began in 1977 with a responsibility to revise legislation for children with special health care needs under Title V of the Social Security Act. This legislation, created in 1935 with a requirement that we "locate, diagnose and treat crippled children," had become both attitudinally and programmatically outdated.

Historically, MCHB began with the establishment of a Children's Bureau in 1912. This new Bureau was located in the Department of Labor, and had as a purpose "to serve all children, to try to work out the standards of care and protection which shall give every child a fair chance in the world..." (Magee & Pratt, 1985, p.1). The next seventy-five years brought steady progress from the provision of services focused on rehabilitating "crippled children" and delivered through the "professional as expert" model, to a broad definition of children with special health care needs and an understanding of the essential roles that families and communities play in meeting the needs of these children and their families.

In 1987, a groundbreaking conference under the leadership of former Surgeon General C. Everett Koop, and jointly sponsored by the MCHB and the American Academy of Pediatrics, resulted in a *Call to Action* to create family-centered, community-based systems of care. This *Call to Action*, articulated in



the *National Agenda for Children with Special Health Care Needs*, sets forth seven action steps:

1. Sustain the national consensus for building community-based and family-centered systems of care for children with special health care needs.
2. Stimulate professional preparation programs to provide new skills needed by providers in changing delivery systems.
3. Support the development of models that resolve cost and utilization issues for children with special health care needs.
4. Provide leadership in the establishment of quality assurance programs for children with special health care needs in managed care settings.
5. Identify and support the implementation of models of family participation in managed care settings.
6. Develop strategies for improving data and evaluation activities to monitor the successes of the National Agenda for Children with Special Health Care Needs.
7. Integrate managed care programs within the community system of services.

Building on this work, the MCHB in 1990 developed a *National Healthy People 2000* objective, which called for the establishment of these new family-centered, community-based systems of care in all fifty states by the year 2000.

As I pause to reflect on our progress to date, I am encouraged. Family-centered care is the "state of the art" and has been embraced by coalitions representing all children and families. The strong family coalitions that exist across the country are effective national advocates on political issues. Families are actively working at policy, program and practice levels: as staff in state programs; as advisors on health boards; as faculty in training programs; as care coordinators for their own and other children; and in many, many other roles. Resources which address the competencies needed to work in our increasingly multicultural society are available in growing numbers. At the same time, a complex array of community initiatives is rebuilding a grassroots network of people and organizations who, in partnership with all stakeholders, are creating vibrant, caring communities.

The principles articulated in the *National Agenda*, which are grounded in a family/interprofessional collaborative strategy, have influenced the legislation of virtually every federal program in the health, education and social services fields. As a result, these principles are now included at the state level in legislation and program policies, and practiced by operating programs all over the country.

How do we continue our efforts to develop universal, sustained relationships between families and the persons who serve them? This new publication, *Partnerships at Work*, leads us in the right direction. It describes the kinds of part-

nerships that need to be developed between families and professionals in their home communities, as well as the kinds of training efforts and practices that will lead to high quality, integrated services for children and families. The partnerships lessons can be used as guiding principles for all families, communities, and regional, state and national organizations in their response to the *Call for Action* in the *National Agenda for Children with Special Health Care Needs*.

We must understand that families thrive when public and private policies respect and support them, even bringing families into the decision-making processes. We must also understand that every family – families new to America and the English language; families who live in luxury on our hilltops; families who struggle daily to put shoes on their children's feet and cereal on the table; families whose children will always learn differently; families whose kids are champion athletes; and families who celebrate each breath their child takes – needs help and partners, at one time or another.

Polly Arango

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**Merle McPherson, M.D., M.P.H.** is the Director, Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, U.S. Department of Health and Human Services. For many years, she has provided consistent leadership in the integration of family/professional collaboration into programs for children with special health needs at federal, state and local levels. Dr. McPherson has held various positions in Maternal and Child Health at the federal level since 1976, and is the recipient of numerous honors and awards.

# Chapter 1



## **Creating the Context: Family-Centered, Community-Based, Culturally Sensitive Partnerships**

*by Kathleen Kirk Bishop, DSW and Polly Arango*

From the very moment a baby enters this world, there must be an expectation that the child and his/her family are part of a greater whole, that partners will assist them, and that no one has to walk through life's journey alone.

Bobby was born at twenty-six weeks gestation, and has been living in the newborn intensive care nursery for seven weeks. He is breathing with the help of a ventilator, and must be fed through a tube in his stomach. Bobby is facing at least two surgeries before he will be able to go home from the hospital. His mother Jane lives approximately eighty-five miles away in this large rural state. She is separated from Bobby's father, Fred, and there are no extended family members within two hundred miles.

Miko, age 16, son of Rosa and Alfredo, and big brother to Maria, age 14, and Jose, age 10, lives in a large urban area in the Midwest. Injured in a car accident this year, he needs crutches to walk. Miko requires physical and occupational therapy, and adaptations at his family home and at school. He would like to find a part-time job after school and on weekends. Both of Miko's parents work to support their children's basic needs.

Chandra, age 2 years, has been living in a foster home since her birth. The state early intervention team has been working with Chandra and her foster mother since the child's release from the hospital, where she was treated for the effects of her parents' cocaine addictions. Her parents, Shawn and Regina, want to conquer their addictions, and make a home for Chandra.

As we consider the kinds of supports and services that families will need to nurture their children in the 21st century, it has become increasingly clear that the current complicated and fragmented array of health, education and social services systems is not responsive to the growing challenges facing families today and tomorrow. Although this nation purportedly has one of the best health, education and social systems in the world, more than 10% of children (6.3 million) in the United States live in extreme poverty, with family incomes of less than half of the official poverty level. Another one in five children is in the ranks of the merely poor. In addition, there are rising numbers of substantiated cases of child abuse and neglect, and the homicide rate among teens has doubled in twenty years (1972-1992) (Gleick, 1996). These families, and many more, lack some of the most basic supports and services, such as adequate nutrition, safe and secure housing and neighborhoods, adequate health care, employment, and appropriate and affordable child care.

When a family gives birth to a baby with special health care needs or has a child with special health, social or education needs, they require all of the same supports and services as other families, and some additional ones. The presence of partners is doubly important. Consider the needs of the families of Bobby, Miko, and Chandra. These families and many others like them need partners who will:

- provide information to the family about the child's condition;
- answer questions;
- assure parents that grief and fear are normal;
- seek resources and supports for the child and family in the community; and,
- find other families who can share their experiences.

We must be increasingly vigilant that these families and all families will receive the necessary health care, education, social services and support that they need not just to survive, but to thrive.

All of these children and families need partners, partners who work side by side with them through all of the stages of life. They need partners who will collaborate with one another, problem-solve together, enjoy happy times with one another, and console each other when things are rough.

A family's partners can be relatives who baby-sit, the pediatrician who diagnoses a chronic condition, the worker who eases a toddler to sleep at the child care center, the nurse at the clinic who knows how to give shots quickly, the social worker at the hospital who arranges for a place for the family to stay, neighbors who gather for birthday parties, teachers who make home visits, and friends who rally around a child in crisis.

Unfortunately, however, the experience of families today is too often one of crushing frustration and dashed expectations. Families search from one agency to another, explaining and re-explaining what they need, with no hope of coordination, cooperation, or collaboration among the many professionals and paraprofessionals upon whom they depend for services and support.

There have been repeated efforts to change the fragmented and overly specialized system of services which exists today, with particular emphasis on coordination and collaboration among professionals (Kane, 1975; Dana, 1983; Abramson, 1989; Andrews, 1990; Hooper-Briar & Lawson, 1994). Nevertheless, interprofessional and interorganizational collaboration continue to be a challenge. Structural barriers exist at both the university preprofessional training level and at the level of implementation with children and families in their home communities.

The idea for this publication came from a previous publication, *Family/Professional Collaboration for Children with Special Health Care Needs and their Families*, K.K. Bishop, J. Woll & P. Arango (1993) and a March, 1996 meeting of the National Commission on Leadership in Interprofessional Education (NCLIE) entitled *The Family Connection: Family and Interprofessional Partnerships*. In *Family/Professional Collaboration* we framed some questions for future inquiry, such as: What effects might collaboration (and partnership) have on professionals within the context of their own professions, agencies and organizations? We also asked about the cumulative and interdependent effects of collaboration on families and professionals, and how to prepare families and professionals for new expectations. The March 1996 meeting was the first Commission meeting at which parents, family members, and young adults at risk for/and with disabilities were significant contributors and participants. At the meeting, examples of family and interprofessional education and practice were presented, and family members and professionals discussed the strengths and challenges of these exemplary programs.

The goals of the meeting were:

- to implement the revised mission statement of the Commission which called for a family/professional partnership (see appendix p.119);
- to demonstrate, to the Commission membership, the importance of family participation in the development and implementation of training programs and service delivery systems which are family-friendly and responsive to the barriers identified by families and professionals;
- to present programs and practices which illustrate the power of family/professional partnerships in the implementation of local, state, and national systems change in health, education, and social work; and,
- to assist university-based, professional training programs in developing recommendations for preprofessional and continuing education programs which are family-centered, community-based and culturally sensitive.

The participation of families as collaborators and partners that characterized the NCLIE meeting also characterizes the partnerships at work in this publication, and offers considerable hope for change in the 21st century. With families as partners, we can effect the kinds of systems change needed to support and provide resources to all children and families, especially those with special health care needs.

Over the past fifteen years, a growing number of families and professionals, federal agency leaders, university educators, and local community leaders have been engaging in conversations with families. These conversations have helped professionals and agencies to learn more about how to provide the kinds of family-friendly services that children and families need to be healthy and productive participants in their communities.

The results of these conversations are portrayed in this publication through examples of partnerships. These examples show children, families, extended families and professionals collaborating in local communities, and with national family advocacy groups, in order to understand and develop the kinds of formal and informal services and supports that families say they need and want. The lessons that emerge from the experiences of these partnerships highlight new and recycled approaches. These approaches require that services are family-centered rather than professionally driven; that professionals see families as people with expertise and resources; that child and family strengths, not problems, are the focus of professional practice; that families whose first language is not English and whose beliefs, traditions and ways of life are different can find services and supports which are respectful of their culture and their family traditions; that professionals collaborate with families and one another; and, that families who have children with special health care needs can find the most facilitating school, social and health services to support each child in her/his community.

*Partnerships at Work* is a publication about successful “in progress” collaborative partnerships at the family, community, state and national levels.

It is about partnerships that have improved a three-generation family's services and supports (*Pat, Glen, and Lucille*).

It is about local community partnerships that have improved the lives of many different kinds of families – those who have a family member in prison, those who have a family member labelled mentally ill, those who have a child with special health needs, those who have a child involved with the juvenile justice system (*Peanut Butter & Jelly, PACER's Team Training on Transition, Project Unity*).

It is about providing services and supports that families ask for and design themselves (*Pat, Glen and Lucille; Project Unity; Peanut Butter & Jelly; PACER's Team Training on Transition*).

It is about community, state and national partnerships between families and professionals, federal agencies and private foundations (*Project Unity, Peanut Butter and Jelly, PACER's Team Training on Transition, Family Voices*).

It is about a partnership that supports families to represent the voices of their children and their families about their health care at the state and national level, in order to educate and advocate for change (*Family Voices*).

Partnership and collaboration are not the goal, but rather the means by which to achieve a goal. Partnership and collaboration are methods and strategies which assist children, family members and professionals in assuring that all children have the opportunity to grow, thrive, and achieve a meaningful place in our nation, and that their families have the necessary supports to be healthy and productive. In the words of Glen Gallivan, "Collaboration is not just about systems, it's about people. It's about our next generation."

If we believe that families truly are this nation's cornerstone, that communities and nations are built by healthy families, then we must encourage formal and informal partnerships between families and those who can assist them. If we believe that health care, education and social work must deliver family-centered care through coordinated teamwork that begins with families and communities, then we will throw aside professional and agency boundaries and make these partnerships work.

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**Polly Arango** is the mother of four children, one of whom has special health needs. She is a co-founder and the current Director of Family Voices, and a founding member of Parents Reaching Out in New Mexico. She is also a co-author of the monograph, *Family/Professional Collaboration for Children with Special Health Care Needs and their Families*.

**Kathleen Kirk Bishop, D.S.W.**, is an Associate Professor and the Project Director of Partnerships for Change at the Department of Social Work, University of Vermont. She has published extensively in the areas of family/professional and interprofessional collaboration, and family-centered social work practice with children and families, especially those with special health needs.



## Chapter 2



# The Gullivan-Hackett-Waters Story: Three Generations of Partnerships

### CONTRIBUTORS:

**Pat Hackett-Waters** is the proud mother of Glen Gullivan. She is currently employed as a Project Director for the Institute for Child Health Policy. With a master's degree in learning disabilities from Xavier University, Pat was an educator for ten years, teaching both regular and special education classes. In 1992 her classroom was named "most outstanding mainstream program" by *Exceptional Parent Magazine*.

**Glen Gullivan** is a senior at the University of Florida pursuing a degree in journalism. He is a member of the Federal Healthy and Ready to Learn Interagency Workgroup. Glen has earned numerous honors and has been the recipient of several academic scholarships. While in middle school, Glen proposed a plan for alternate seating for the disabled at Riverfront Stadium, which was under construction in Cincinnati, Ohio. The plan was approved and implemented on opening day, April, 1988.

**Lucille Hackett**, Pat's mother and Glen's grandmother, worked for thirty years as an accountant during the day and as a nightclub cashier at night. In Pat's words, Lucille is the "team specialist" for the family and "the critical piece that has kept us together."



Chapter 2 highlights a three-generational family, their lived experience and the lessons they have learned. Together and individually, the Gallivan-Hackett-Waters family demonstrate the relationship between establishing partnerships and improving the quality of life for children with special health care needs and their families.

*Glen Gallivan was born in Massachusetts on May 24, 1973. When he was nine months old, he was diagnosed with spinal muscular atrophy, which causes wasting of the voluntary muscles. Breathing difficulties were an immediate concern, and health crisis management and avoiding pneumonia were early priorities for the family.*

*I feel any grandparent who hasn't entered into the lives of these kids is missing a lot...I wouldn't trade it for anything else in the world, because I just love these two so much.*

Lucille Hackett

PARENT/GRANDPARENT: Although Pat's marriage to Glen's father ended in divorce four months after Glen's diagnosis, and many extended family members were too overwhelmed by the situation to be helpful, Pat was not without family support. Her mother, Lucille, was very involved from the beginning: "If ever anyone anticipated being a grandma, that was me. I was overjoyed." When it was clear that Pat and Glen needed her, without hesitation she quit her job, sold her home and moved in with her daughter to become the baby's daytime caregiver. Pat acknowledges that taking care of Glen's physical and medical needs was a huge accomplishment for Lucille, because of the anxiety the situation evoked. "She found the strength to do some things for Glen that she couldn't do for anybody else. It was very hard for her, but she met the challenges head on. I give her a tremendous amount of credit." As a partner, Lucille accompanied Pat and Glen to all of his medical appointments "because I had to learn too." Glen's physicians became accustomed to her presence, and she always felt accepted by them as an important part of the family. She took Glen to school every day and became a volunteer there, with the result that she developed relationships with his teachers. She became Glen's ally and his confidante, and shared some of her interests (like sports) with him. Despite all that she has given, Lucille continues to talk about the experience of being Glen's grandmother in terms of what she has received. "I feel any grandparent who hasn't entered into the lives of these kids is missing a lot...I wouldn't trade it for anything else in the world, because I just love these two so much."

In 1977, Pat married Jack Waters. "Glen proposed for us. He wanted Jack for a daddy." Partly because he himself had coped with multiple health issues as a child, Jack was able to "form an incredible bond" with Glen, and he became another essential partner for mother, grandmother and son.

**Remember that a child with special health needs is still a child:** The life-threatening nature of Glen's condition was the basic reality for the family in the very early years. Pat says: "In the beginning the emphasis was on medical management and not on enjoying life. Everything was about Glen as a patient and how to avoid death, and we forgot that he was also a little boy who needed to grow." As Glen's health crises became less frequent, it became apparent to Pat that

he still needed to be treated as a child, to have fun and be involved in appropriate developmental activities. She had been totally occupied with meeting Glen's physical needs and doing research to learn as much as possible about his illness. Advice from Glen's pediatrician to spend less time in the library and more time in the toy store helped Pat to seek creative ways to meet his developmental needs through play.

Very early on, Pat learned that her expectations for her son were sometimes different from those of the professionals in his life. When it was time for toilet training, what she heard was: "Why toilet train him when it will just make it harder on you? It will be much easier to manage him if you just continue to change him no matter how old he becomes." In contrast, Pat viewed toilet training as an age-appropriate task that Glen could master, and which would probably also allow him access to more integrated settings. Pat says that this experience exemplifies her early struggles to advocate for Glen. "People did not see the same vision as I did. And as frustrating as it has been, I have never gotten used to it. Glen is a person. So often professionals only see the disability, the diagnosis or the barriers."

*Glen is a person.  
So often professionals only see  
the disability, the  
diagnosis or the  
barriers.*

Pat Hackett-Waters

PARENT/ SOCIAL WORKER: Adjusting to having a child with a chronic illness and multiple medical emergencies, and managing the rest of life as well, was very challenging. Pat says: "There were ups and downs, but never was everything up at the same time. I always think back to the old Ed Sullivan show and the entertainer who kept spinning more and more plates. I am so thankful for that image, because I am that person; that's my life. It's just always something." Pat remembers asking a social worker, "When is this ever going to end?" and the woman's reply has remained with her. The social worker said that with chronic illness, you just learn to adapt better. You learn to problem-solve and to forecast what's going to be an issue, and you learn to realize what you can fight and what you have to let go. Pat heard the social worker's message, and became determined not to experience everything as a crisis. She backed off a bit and saved her energy for the situations where it was most needed. This has proved to be an essential survival skill.

**Coordinate services to meet the complex needs of children with special health care needs:** When Glen was born, Pat thought that their relationships with professionals would be like most families', limited to the pediatrician and a series of educators as he grew. After his diagnosis, "the number of professionals in our world increased tenfold. We now had on our service team a neurologist, a nurse, an occupational therapist, a physical therapist, a respiratory therapist, an orthopedist, an orthotist (a professional who works on braces) and the person who helped us to balance these new experts in our lives, our social worker. As the years passed, the team further expanded to include teachers, a pulmonary specialist, a nutritionist, a gastrologist, an ear, nose and throat specialist and a therapeutic recreationist. Each one was an expert in his/her field, but many

lacked understanding of how they all fit together. As a young parent, I was eager for advice, but sometimes the recommendations of these different professionals contradicted each other. Trying to figure out what to do, what to choose, was perplexing. While many of them mailed reports to each other, I wondered whether they had the chance to exchange thoughts, ideas, recommendations before offering advice to us. The professionals in our family's life practiced the way they had received their professional training, in segregation from each other. Although each had an integral role in our lives, they seemed to be strangers to each other. While sometimes they knew of the existence of the others, they weren't familiar with the services or skills each offered. That was for the family to figure out. And this situation created stress for the professionals as well as for us. Many times professionals expressed frustration that their professional training had not adequately prepared them to work in a team approach with multiple experts. My role, in addition to being mom, seemed to be to serve as a conduit for networking and information-sharing. I often wondered why they hadn't learned to team their expertise without depending on us."

**Recognize that inclusion of children with special health needs can benefit families, professionals and programs:** Finding a nursery school for Glen presented new challenges. The family investigated eight different schools before they found one that would accept him. One of the schools told them that they would have to take out an insurance policy in case Glen's wheelchair hurt another child. In Pat's words, "He was quadriplegic and couldn't even pick up a pencil, never mind push his chair into anyone." Nevertheless, those were the kinds of fears that people expressed. One place wanted the family to join a church; others "just flat out refused him." A turning point came when Pat learned about Head Start, a program whose funding required them to serve children with disabilities. Finally, here was a place where there were children who were disabled,



although Glen was the first child with such a severe physical disability. Because they were accustomed to difference, and because his presence could help the school to obtain additional funding, Head Start welcomed him “with open arms.” This experience introduced Pat to the idea that her son had gifts that could be attractive to programs, and was an early lesson in the power of persistence.

There were other lessons as well. Glen attended two Head Start programs, the first of which stipulated that while he was there, Pat had to stay outside in the car so that she would be available in case of a medical emergency. Based on this experience, she assumed that this was the way that life was going to be. Consequently, when Glen changed to a different nursery school, Pat continued to sit outside every day. After a week, one of the staff came out, knocked on her window and asked why she wasn’t going home. This was a significant experience for Pat, because it gave her permission to physically separate from Glen, and because she realized that this school was willing to share some of the responsibility and truly be her partner.

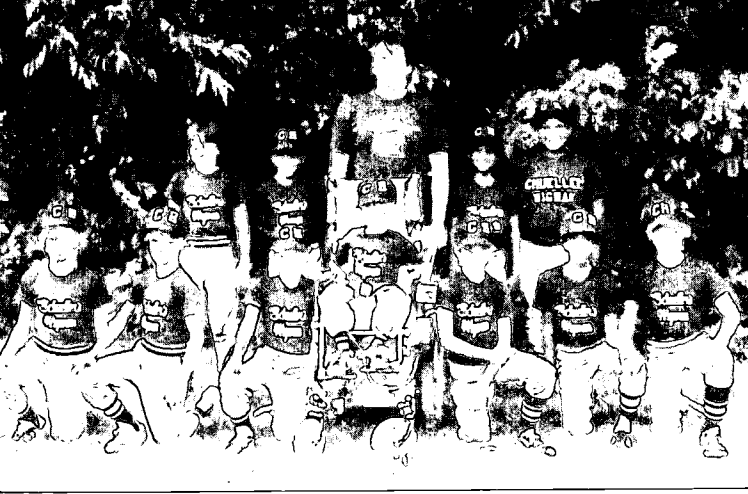
Every child deserves  
a horizon, not a box.  
Pat Hackett-Waters

The separation was in some ways easier for Glen than for his family. Pat, not yet having developed trust in the school, extracted a promise that the staff would call if anything at all happened. One day when a missed ball caused a bloody nose, Pat and Lucille “made a mad dash over to see Glen.” The little boy’s response to their presence was, “Just wipe my nose and leave because school’s not over yet.” Pat says that these “normal moments” helped to sustain the family and to reinforce for them that Glen was more like other children than unlike them.

#### PARTNERSHIP EXAMPLE

PARENT/PHYSICAL THERAPIST: Once Glen began to participate in the regular life of his community, the concern of the family turned to finding the kind of seating that would allow him to enjoy his environment as much as possible. Although at that time motorized wheelchairs were only authorized for college students, Pat believed that it was essential for Glen to be mobile, because she knew that “learning was happening all around him, not just right next to him.” The family had moved from Massachusetts to Ohio, but had maintained a very strong relationship with a physical therapist in Boston who understood what they were trying to achieve. She found a doctor there who wrote a prescription which then had to be honored in Ohio. As a result, Glen received his first motorized wheelchair when he was four and a half. According to Pat, being mobile greatly broadened his horizons, and the clear emotional growth which resulted helped to demonstrate to professionals the importance of working with children’s potential and of maintaining flexibility in systems to meet the needs of individual children. In Pat’s words, this experience brought home the point that “every child deserves a horizon, not a box.”

Glen continued to have periodic medical crises, some of which were so serious that they required the family to resuscitate him. However, his developmental and educational needs remained a focus. When it was time for Glen to enter first grade, schools were reluctant to admit him because he required a different level of support. Although there



were special schools for children with disabilities, they didn't have the same expectations that Pat had for her child. She made the decision to enroll Glen as a regular student, because she wanted him to have the benefits that were available to other children. This was a difficult time for Pat, who had grown accustomed to positive reinforcement from the medical system for her skill and involvement in Glen's care. She says: "I had been trying to be the dutiful parent. I

*had been applauded because I was so compliant in taking care of Glen's needs, and I had been put on a pedestal because I had been so proactive medically with him, and now I was going to shake the system because I didn't believe in what the schools were packaging. I didn't know if I was ready to get off that pedestal. It was a little bit of a challenge, but I knew in my heart that I needed to do this for Glen. So I took a little bit of the old sixties spirit and decided to buck the system."*

**Change professionals' attitudes through familiarity with children with special health needs:** Pat reports that the school system was actively trying to find a reason to remove Glen from the school. Many different people came into his classroom at various times to observe him, which was obvious to Glen and increased his discomfort. However, the family did not back down, and gradually change did occur. Although the kindergarten teacher, daunted by Glen's disability, often excluded him from class activities, the children found acceptance easier. For example, in gym class when they did an exercise with a large parachute to help the children to develop gross motor skills, the children would bring Glen into the circle, and hold his hands so that he could have the experience. The teacher would then come behind him and put him on the sidelines. Being five year olds, his classmates would just go back and get him, because they knew that Glen needed to be part of the group. The children understood inclusion; it was the teacher who had the difficulty. But getting to know Glen over the period of a year, and watching the impact he had on the other children changed the teacher's perspective. She felt proud to be part of the movement toward inclusion, and she then became an ally who helped to prepare the next year's teacher. This was a trend that continued. Glen's first grade teacher enjoyed her experience so much that she chose to move on with the same group of children to second grade. The same thing happened again later, which Pat believes relates to a "uniqueness" about the class, a uniqueness which she attributes in part to Glen and the community spirit the children learned from being with him.

**Employ interprofessional collaboration to benefit families and professionals:** Pat says: "When Glen was starting school, a new movement was underway, 'multi-disciplinary teams.' Prior to this time, we had usually just sought advice from medical professionals. Now that he was school-aged, we needed advice that was aimed at the whole child, not just the sum of his parts." Glen had the opportunity to receive multi-disciplinary services through a University



Affiliated Program (UAP) in Cincinnati. He was assessed by each discipline, which was not a new procedure, but when it came time to present the findings, these professionals shared their reports with each other and developed a team plan and recommendations. This approach made a big difference for Glen. For example, Mrs. Renner, who was soon to be Glen's first grade teacher, was invited to hear the recommendations of the multi-disciplinary team. She had never before experienced this kind of support and insight on behalf of an incoming student. Knowing that she had a team of experts to help guide her, Mrs. Renner was able to more easily accept Glen into her classroom. This helped Glen to begin his education in an atmosphere of inclusion and support.

**Maximize opportunity for children with special health needs in schools and communities:** Glen believes that attending public schools as a regular student was an invaluable experience. As he says, "I was a regular student, who went to the local neighborhood school for the day, just sitting there doing my homework, not doing my homework, just a typical student." He views this opportunity to make friends and to be part of a group as critical to his development. Glen believes that "learning and experiencing" with his classmates significantly contributed to his current success.

*As Glen grew, Pat learned another lesson, that she needed to say no to him and really mean it. "I needed to give him more structure in some situations instead of just handing him the world. I needed to put life on the front burner and the disease on the back burner." This realization helped the family to give Glen the message that no matter where he was in life, they expected him to be productive. He went back to school as soon as possible after every medical crisis. "If his brain was working, his butt was out the door."*

**Learn from families about how to take risks and overcome obstacles:** When Glen was in third grade, his scoliosis (curvature of the spine) worsened to the point that the family had to make an extremely difficult decision. By ten every morning his chin would be on his desk, and although he continued to write his schoolwork from that position, Pat saw that his condition was deteriorating and that something had to be done. After some intense research, she decided to investigate the possibility of a surgical procedure, spinal fusion, which would allow him to sit upright. This surgery was not commonly performed in situations like Glen's because of the risks of anesthetizing children with severe respiratory problems. The family agonized. Were they considering something that was truly going to have lasting benefits? Was it worth the risks? In the end, they knew that Glen's other choice was to be bed bound and eventually die, and that they had to try, because "even as a third grader he had a life and a lot of will to live."

Persuading Glen's medical service providers was the next obstacle. His orthopedist, neurologist and pediatrician all tried to discourage the surgery. Pat struggled to understand and work with "the professional and political dilemmas" that influenced the physicians' positions. With help from a social worker who was a regular customer at the restaurant where she worked, Pat learned that "when people are

*We needed advice that was aimed at the whole child, not just the sum of his parts.*

Pat Hackett-Waters

*I needed to put life on the front burner and the disease on the back burner.*

Pat Hackett-Waters



saying no, it's not always about you. Often it's about what's at stake for them." In the end, her persistence won out, and the surgery was scheduled.

*...when people are saying no, it's not always about you. Often it's about what's at stake for them.*

Pat Hackett-Waters

**Learn from families' creative approaches:** The family began preparing Glen for surgery. Pat did music relaxation with him every night, and relaxed his muscles by compressing them with her hands. They listened to the theme from *Chariots of Fire* to convey to Glen that he was "going for the gold. And it takes a lot of sacrifice and effort, and sometimes it's not comfortable and sometimes it's painful, but the outcome is what's important." Since Glen was going to have to have a tracheostomy, the family prepared him by eating breakfast every morning with a picture of a person with a tracheostomy. They did this for four months, so that Glen became very familiar with what it would look like. When Glen was admitted for the surgery, he was nine years old and weighed only twenty-seven pounds, but he was determined, and he was prepared.

**Learn from families how to create change:** Two days before the surgery, various professionals were still trying to talk the family out of it, not only because of the risk to Glen, but also because if this operation was successful, they knew that other families would come forward wanting the same procedure for their children. Pat was very aware that there was more at stake than her child's future, and it helped to maintain her courage. Glen came through the surgery and, as they had hoped, it changed his life by allowing him to experience the world from a normal sitting position.

While Glen was in the hospital, Pat's advocacy continued. She negotiated with the hospital about the visitation schedule because "I needed to be with my son." In her words, "Those were the days of ten minute visits every three hours, and I asked them to think about allowing visits twenty-four hours a day. In exchange, I promised to show them a model that would work. Even on difficult days, I would sleep every night in the chapel, and then go upstairs during Glen's waking hours." This schedule not only brought substantial benefits to Glen and

his family, it also helped to change the system. The hospital now has a twenty-four hour visiting policy. As anticipated, another result of Glen's successful surgery was that other children were considered for spinal fusions. The physicians now viewed the procedure a little differently, and the hospital made the necessary changes in their admissions policy.

*Pat's life changed too, when one of the nurses from the hospital recommended her to be a family representative to the first national family-centered care meeting (Association for the Care of Children's Health). This was the beginning of years of involvement in another level of advocacy, which Pat knows would not have happened if she had not stood up and said, "This is what I want for my child." It was also the beginning of a new family for Pat. She discovered that no matter what their children's diagnoses, all of the parents shared common hopes, dreams, frustrations and fears, and her family partners have become "closer to me than my blood relatives."*

**Look for "win/win" solutions to problems:** When Glen was ready to start fourth grade, the school administration believed that they would have to put in an elevator in order to accommodate him, and therefore wanted him to go to another school. Pat considered the situation and suggested that the teacher go to the floor where Glen was and teach in one of the empty rooms. "In that way, everybody could be happy. Glen could stay with his friends and the school did not have to think about putting in a \$65,000 elevator." This experience taught Pat an important lesson: "I always tried to find a way to do things that would meet both Glen's needs and the school's needs."

#### PARTNERSHIP EXAMPLE

**FAMILY/ORTHOTIST:** The family continued to search for "integrators" for Glen, ways to maximize his participation in life. They were guided in this by a comment that an orthotist had made when Glen was a baby: "You're going to live your life the same way; you're just going to have a little more equipment. Keep living the way you would have without the disability." Since sports had always occupied an important place in the family, Pat decided that Glen would do what other children do, for example, participate in Little League baseball. He began on T-ball teams, and his involvement continued all the way up to high school. Early on he was the equipment manager because the wheelchair was helpful to carry equipment. He was good in math, so he became a scorekeeper and then moved up to statistician and then announcer.

**Focus on strengths rather than obstacles:** Trying to give Glen the usual childhood experiences always involved bucking the system. In Pat's words, "We were never once greeted with, 'Of course, this can be done.' It was always, 'Why are you even thinking this way? Don't you understand your child's limited future?'" But Pat consistently tried to educate people by reminding them that they, too, were terminal: "When your time is up, it's up, but there is a lot of life in between, and Glen chooses to live." It was very difficult to find professionals who shared the family's vision. Coaches, who are trained to work with potential rather than problems, turned out to be an exception.



PARTNERSHIP AT WORK

STUDENT/COACH: When it was time for Glen to transition to junior high school, he was aware that it "could be a difficult situation for me." The school was "a twenty-five minute ride from my house to a very rough, blue-collar, inner-city neighborhood in Cincinnati." However, when Glen learned that football practice started before classes began, he contacted Coach David Jones and asked him whether there was anything he could do to be part of the football team. The coach immediately invited him to begin attending practice as the equipment manager. "This worked out great, because every day we practiced, I made new friends, and this helped me when school began. Not only did I already know people, but they were some of the toughest kids in school. No one ever thought of messing with me." With Coach Jones' encouragement, Glen later became the announcer for the basketball team, and even assumed some coaching duties for both football and basketball. Glen is grateful to Coach Jones for these experiences which "allowed me to develop mentally and to achieve a measure of popularity and respect among my classmates." A creative mentor, committed to all children, made a big difference for Glen.



Although Pat had been trained as a teacher, during Glen's early years she chose not to have a professional career that would require daytime hours. Knowing that her son's medical and school needs would consume her days, she chose to do waitressing at night, because it would provide adequate income, and also allow her to be with Glen during the day. When Glen was very young, he experienced frequent medical crises which required that he go into the hospital for a week or two. Later, the hospitalizations were more spaced out, but the family dealt with multiple crises at home. Pat says that she had to be an outstanding employee because of her frequent absences. She was fired once when she couldn't come to work because Glen was in intensive care and in danger of dying. Consequently, she knew that she had to carve out a reputation for excellence so that customers would ask for her, and her employer would hate to lose her.

PARTNERSHIP AT WORK

PARENT/EMPLOYER: When Pat finally found an employer who understood the pressures she was feeling, she stayed in that job for nine years. One of the ways her employer showed his support was by offering to testify on behalf of Glen's school placement in front of the school board. When Pat asked him why he was willing to do that, he said, "Because I care about you as a person, you're a great employee, and you make more money for me when things are good for you and Glen." Although self-interest was a factor, this man was willing to care. When Glen had his spinal fusion, Pat's employer went to visit him in the hospital. Since few people visited when Glen was in serious medical trouble, that was another time when Pat really appreciated his caring.

**Identify and nurture families' strengths:** While Pat was waitressing and caring for Glen, she "ventured a little bit into the advocacy world," working part-time at the Parent Training and Information Center and occasionally making presentations for groups of parents and professionals. At one of these presentations at Xavier University, Pat met a special education director named Anna Mayans, who became a mentor. After hearing her speak, Anna felt strongly that waitressing wasn't Pat's calling, and as Pat reports, Anna wasn't afraid to "get in her face" and tell her what she thought. Anna believed that Pat should be earning her living by teaching. Because of the potential for Glen's needs to take her away from the children, Pat had been reluctant to make a commitment to a class. However with Anna's encouragement, she took the first step of becoming a substitute teacher. Three years later, when Pat acceded to an urgent request from the principal to take over a challenging third grade class, she was launched as a full-time teacher. Anna continued to urge Pat to develop her potential, and she soon returned to school to obtain a master's degree in special education. Pat says that because of all of the demands of her life, she is not sure that she could have "made that leap" into teaching without the support and encouragement of professional mentors.

PARENT/PARENT: Pat also had to learn how to meet her own needs. In the early eighties she met another mother of a child with a disability who became a peer mentor. They did things "mom to mom" together, and provided each other with support. Since, like Pat, Mary was very interested in learning more about how to help her child, in 1981 she suggested that they go to The Association for Persons with Severe Handicaps (TASH) conference. The conference featured Lou Brown and the concepts of normalization and inclusion, which were beginning to be implemented with children with developmental disabilities, and Pat thought that they might work for Glen. Since it was very difficult for Pat to leave Glen, her friend's encouragement was key. Pat says: "I was afraid to leave him. What if he died? She assured me that he would survive the separation, and reminded me of the reality that any of us could die at any moment. She convinced me that what was important was deciding what I was going to do as a parent, what my plan was for Glen."

PARENTS/ORGANIZATION: Pat, Mary and four other parents arrived in Denver for the TASH conference, with no room reserved at the hotel and without having registered for the conference. Right away Mary approached Lou Brown and persuaded him to donate a room for the six of them. Later, when Lou Brown became aware of the financial hardship that the registration fee presented for Pat, he offered her a position as a door monitor, which she gladly accepted. It was the first time that TASH ever used families in that role, and it was the beginning of a policy that families could attend free of charge if they worked at the conference and lived within fifty miles of the site. The experience of the conference taught Pat that there were

people who were willing to be supportive if they knew what was needed, and it provided another lesson in the power of determination. "There was nothing in place to let us go, but we were determined to be there anyway."

Pat continued to find opportunities to develop as a parent leader. When Glen was in eighth grade, there was an incident where he had to be resuscitated at home. This resulted in an admission to the hospital during which, according to Pat, "everything you could imagine went wrong." Because of that experience Pat wrote a letter to Surgeon General Koop, whom she had heard talk about family-centered care. The letter thanked him for his leadership in this movement, and also made some suggestions for changes in policy and practice. Dr. Koop read her letter and sent it on to the Maternal and Child Health Bureau. The Division of Services for Children with Special Health Needs, under the leadership of Merle McPherson, M.D. responded, and Pat was asked to be part of a planning grant for the Pathfinders conference in 1988. One of Pat's contributions was the suggestion that every project should bring a family, which had never been done before. During the conference, Pat belonged to a work group which was to report out to the whole assembly at the end. She admits, "I was very nervous because our recommendations were kind of nouveau and radical, but the person beside me said, 'Remember, they paid you to come and talk, so don't hold back.'" That person was John Reiss, who later became Pat's employer.

#### P A R T N E R S H I P E X A M P L E

PARENT/PROFESSIONAL: Pat cites the story of her relationship with John Reiss as an example of her view of her life as an "incredible trip." During the Pathfinders conference, Pat had a conversation with John about his employer, Steve Freedman, who was Executive Director of the Institute for Child Health Policy and whose work was familiar to her. Pat says, "I was always looking for people who believed like me, and Steve had written a wonderful article on power brokering at the state level and how to get your message across and be a change agent. I had taken his ten steps and used them to get my son into middle school. The article wasn't written for my situation, but I was able to take his good information and make it work for us." Later when the family moved to Orlando, Pat saw John again. He got her involved with some committees and they worked together on several projects. In anticipation of health care reform, Pat believed that she needed to relocate her family again, to an area that had more doctors per capita. When they chose Gainesville, Pat asked John to let her know if there were any job openings, which led to her current position. John is one of the professionals who "recognized something in me that I hadn't acknowledged" and helped to nurture her growth as a parent leader.

In reflecting on some of the other factors that have helped her to meet the challenges of her life so successfully, Pat cites having had to overcome difficulties in her childhood and having grown up in the sixties. She says that the climate of the times gave her the message that she didn't always have to agree, as long as she had an alternative idea. In addition, her father was a union negotiator, as she herself was during her time as a waitress, and from this she learned to "neutralize the tension in some conversations and still

go for what I wanted. You have to work with the people who are in your way and find ways to meet their needs in order to get what you want.” Irish humor has helped the family through tough times, as has a constant effort to look for the good in every situation. Pat believes that something positive has come out of every tragic event. And, of course, her love for Glen was the basis for everything. “I think that a lot of mothers, because of their love for their children, go above and beyond anything they imagined they could do, or would ever do for themselves.” Although they continue to marvel at what Glen has accomplished, the family also recognizes that “This is what you do in life, you participate.”

**Model advocacy so that children with special health needs learn to advocate for themselves:** Some recent events clearly demonstrate what Glen has gained from his mother’s modeling of determination and advocacy. Because of some severe health problems which he experienced in January, 1997, Glen had



to drop out of college for the semester. This was the first time that he had not been able to bounce back quickly enough to stay in school. Although he was able to continue his part-time job, the absence of classes left him very bored, and he needed something else to do with his time. This spring Glen, who is a lover of horse racing and skilled in the art of betting, went to the Churchill Downs website, and saw that there was going to be a journalism seminar a week before the Kentucky Derby. Admission was competitive, but to Glen it seemed to be a wonderful opportunity to interview the owners, jockeys, etc. – “about inside kinds of things.” He applied and was accepted, which he thought was great, but he also had some other ideas about how to get the most from this experience. He thought that if he was going to be that close to the Derby, he should be able to attend and report on it. The local newspaper said no, but Glen was undeterred. Two years before, he had had an assignment for a journalism class to interview someone in the field. At that time he had told his dentist about the assignment (they’re both big Gator fans) and it turned out that the dentist was able to connect him with a sportscaster from the local university radio station. Since they had developed a good rapport during the interview, Glen thought that this man might be able to help him in his quest to go to the Derby. The sportscaster listened to Glen’s idea and told him to call in a few days. Knowing that it’s harder for people to say no in person than over the phone, Glen chose to go to the man’s office for his answer. Although they couldn’t fund his hotel stay, the radio station did ask him to call in reports and offered to help him get a press pass. Glen went to the Kentucky Derby and called in live reports for three days. He did so well that he was also asked to cover the Belmont Stakes, which he happily accomplished in five ten minute radio broadcasts.

*My goals are  
to stay in school,  
be productive  
and become  
a taxpayer. I  
want to earn  
a living, and I  
know I can.*  
Glen Gallivan

Glen's proud mother says: "For him this kind of thing is just like rolling over, because he grew up watching us model these behaviors. He understands what it takes to change a system and he's doing it himself. It's about not accepting the no, because if we had listened to some of the no's (Why bother doing the surgery if he's not going to live? Why try to teach him how to write because he'll never write?) Glen's life would be very different. People don't say these things out of cruelty. They speak from their experience, and we have to ask them to think about a new experience." Glen's full life is a tribute to the power of partnerships and to the incredible strength of this family, who let nothing stand in the way of their vision.

## RECOMMENDATIONS FOR PROFESSIONALS:

**Be respectful of and responsive to families:** As both the mother of a child with special health care needs and a professional educator, Pat has a dual perspective on the issue of family-centered services. Despite all of her experience as an advocate for her family, she learned an important lesson when she began teaching. "I thought I had all the answers to everything. I knew family-centered care, I knew mainstreaming, I knew health systems. And boy, did I get a lesson from my classroom. I was doing things the way I thought they should be done, and all of a sudden families were saying to me, 'Wait a minute. This isn't what we want.' And as a professional I had to stop, and really become family-responsive."

**Work together to fill gaps in services:** As a mother and as a teacher, Pat has spent twenty-three years advocating for Glen and other children. It saddens her to note that the same problems that she fought to overcome for Glen and for her students have not diminished. In fact, more and more children lack access to basic necessities such as a good education and adequate health care. To tackle these issues, Pat calls for a "renewal of the spirit that we had in the sixties. I invite you to reestablish the camaraderie that we had then, to add a little of the wisdom of the eighties, and take out the greed of the nineties." Pat believes that we can solve "these appalling systems failures" if we join together with purpose and use what we know. This joining together involves more than sitting at a table speaking for our particular disciplines. "It's managing ideas and merging them. It's blending our training experiences and gathering our strengths" to meet the needs of children. And Glen adds the reminder: "Collaboration is not just about systems, it's about people. It's about our next generation."

**View professional roles flexibly to help and support families:** When professionals look at families like Pat, Lucille and Glen and what they have accomplished, their response often is, "They are exceptions. The families I work with are too poor, or indifferent or unskilled (or whatever) to partner with me." Pat has a strong answer to this assertion, which is that professionals must work with the families wherever they are. "I taught in the inner city. I would do a really good job in the classroom, and the children would go home and the world would be falling apart for them again. It took me ten years to realize that I had to do more than just work with my students in school. I gave them a nice solid education from 8 to 2, and then from 2 to 10 at night it was pure hell for them. What I chose

*Collaboration is not just about systems, it's about people. It's about our next generation.*  
Glen Gallivan

to do was take a look at the next dimension and work with families. Wherever they were in their lives, I would offer what I could to help to get them to the next level. Sometimes I helped parents to get their Graduation Equivalency Diplomas (GEDs). Sometimes because of my background in vocational education I was able to assist them to connect with resources. Sometimes a bunch of us would get some money together to buy technical books for families."

#### P A R T N E R S H I P E X A M P L E

CLASSROOM TEACHER/PARENT: "I have one family in mind. The mom is a real dynamo. She weighs 89 pounds and her son has cerebral palsy and weighs 115 pounds. When Chris first came to my classroom, the family lived in a two story building, which meant that she had to carry her son upstairs every day. I mean, it gets a little old, and a little tiring, and when that mother's back goes out, what happens? So we worked with HUD (Housing and Urban Development) to get them a one floor apartment. We worked with family needs first. The next thing we did was teach Chris how to use a computer to help him in the classroom. The by-product of that was that his mother also got to learn the computer, which gave her the skills and confidence to join the workforce as an aide in a classroom. Now she has maintained this employment for four years, and she never thought she would have the chance to work. What a difference we made for that family! To this day we keep in touch. She is so grateful that I not only gave her a push, I gave her a hand as well."

One of Pat's first experiences as a kindergarten teacher was with a child who was experiencing an unusual kind of seizure. "Every hour on the hour he would go attack somebody, and then have no recall of the event." Since this was a child from an inner city neighborhood who had very limited access to medical care, Pat brought him and his mother to a pediatric clinic with her. "He was in one set of rooms with his mom, and I was in the other room with my son. And the resident physician came and said, 'This family next door says they're with you.' And I said, 'Yes, they're with me. That's my student, and I expect you to help him out so I won't drive you nuts.'" Sometimes teachers and other professionals have to extend themselves to help students to get what they need.

**Integrate family members fully into organizations:** Many organizations hire family members to represent a family-centered perspective, but then assign them roles that are tangential to the core function of the organization. Pat and John Reiss, her current employer, both believe that family members bring many skills, and that the whole organization benefits from tapping into those skills and making the contributions of families an integral part of its essential functions. Besides infusing the organization with a critical perspective, John says that family members provide a personal and professional challenge that, while uncomfortable at times, has very positive impact. Families "force us all to try to integrate 'we' as professionals and 'we' as people." They challenge attitudes and behaviors, and help organizations, and the people who comprise them, to be true to their values.



## RECOMMENDATIONS FOR TRAINING:

**Train teachers and other professionals to work with children with special health needs:** Pat believes that teachers are becoming more comfortable with children with disabilities because they see more of them. Glen was the first generation of mainstreamed children. “For years he was the only person in the schools who was in a wheelchair, and when he graduated, he was the only one of four thousand students who was in a wheelchair. But in this next generation of students, I believe that there are more kids who have visible disabilities and invisible disabilities.” However, rather than counting on teachers gradually becoming comfortable with these children, Pat recommends early exposure, while they are still in training. “Get those students out into places where you know kids with disabilities are. Make sure these kids become a familiar sight. People’s attitudes change with familiarity, by taking the unknown and making it known.” Listening to children and families should also be part of training. “Find families in your communities who are willing to tell their stories and invite them and their kids in to share their experiences.”

**Help students to confront their fears:** Pat worked with many student teachers who had fears about working with children with special health care needs. “The first thing we would do is an honest attitude check. Get in touch with those feelings, the reasons why you are afraid. Many times it’s because you don’t know how to handle certain situations, or you’re afraid the child is going to die in your classroom. I usually hit the big fears first. Tell me what it is you’re really afraid of, and let’s deal with that.”

**Expose students to experienced practitioners as role models:** Another strategy is to bring into training situations speakers who can talk about actually doing, working with children with disabilities. However, Pat warns, “They must also be honest, because we don’t want to just talk about the good news. These children do present challenges; it takes a lot of effort to get to the good news.” Expose students to pockets of excellence. There are some wonderful, experienced professionals out there, who haven’t burned out, and who are very eager to pass on what they have learned to the next generation.

**Teach students how to negotiate and advocate:** Because the people in power may say no, students need to learn how to maneuver around no and change it to yes. Pat taught negotiation to her students by teaching them some basic problem-solving techniques and then giving them problems to solve that were concrete and related to something that they wanted. She put these issues into context for the students by saying that often when people say no, it is because they can’t think of a way to give you what you want without too much cost to them. These students’ efforts proved that advocates who are creative problem solvers can frequently come up with solutions that work for everyone.

**Train professionals to seek out and work with their professional partners:** Pat knows of many families whose children require the services of numerous professionals and who carry the burden of facilitating interprofessional com-

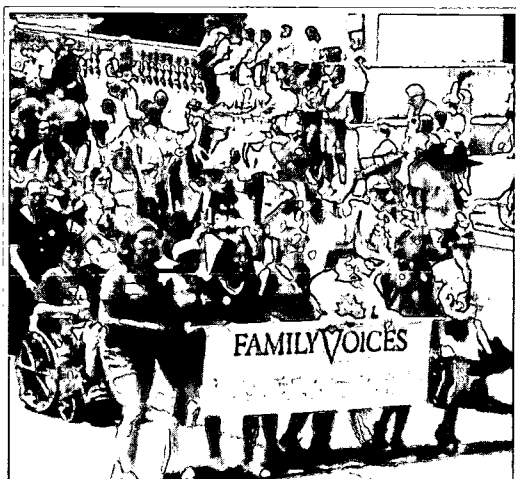
munication and practice. Many of these families would welcome sharing this responsibility, which can be exhausting for them. Pat's message to educators is, "It would be very helpful if your students would graduate with the idea, 'I am going to find the partners who are dealing with the same kids.'" They need to learn to think of themselves as part of a team, and to share responsibility for ensuring that the team functions smoothly.

## **CLOSING THOUGHTS:**

For families and professionals, the Gallivan-Hackett-Waters family story brings a message of hope. This family's example makes it very clear that with courage, determination, creativity, and a touch of serendipity, obstacles can be overcome and goals can be reached. The other crucial message of this story is that no one can do it alone. Many people supported Pat, Glen and Lucille in their remarkable achievements. We all have numerous opportunities to become partners for families and professionals. When these opportunities arise, we need to remember this example of the power of partnership and say yes to involvement and caring. And when we find ourselves in challenging or discouraging situations, we need to think about who our potential partners are, and seek them out. Whether our goal is to support one family or to reform a whole system, collaboration with families and other professionals can help to make it possible.



## Chapter 3



# Family Voices: A Grassroots Public/Private Partnership

### CONTRIBUTORS:

**Polly Arango** is the mother of four children, one of whom has special health needs, and a co-founder of Family Voices. She is a founding member of Parents Reaching Out in New Mexico.

**Betsy Anderson** is the mother of three children, one of whom has special health needs, and Family Voices Project Director for the Partners in Communication program. She is based at the Federation for Children with Special Needs in Boston, Massachusetts.

**Julie Beckett** is the mother of Katie Beckett, for whom the Medicaid Waiver\* was named. Based in Iowa, she is a health financing expert and the National Coordinator for Family Voices.

**Josie Woll** is the mother of three children, one of whom has special health needs. She is the Director, Preschool Program, Sultan Easter Seal School in Honolulu, Hawaii and the Chairperson, Board of Directors, Family Voices.

**Trish Thomas** is the mother of two children and the National Outreach Coordinator for Family Voices in New Mexico. She is a member of the Laguna Tribe.

**Maggie Schwarz** is a social worker with Children's Medical Services, New Mexico Department of Health, and the mother of two children with special health care needs.

**Bob Craig** is the father of two boys, one of whom has special health needs, and a member of the West Virginia Family Support Council, Family Voices and the West Virginia Assistive Technology System.

\* In 1981, Julie and her family succeeded in having income eligibility limits for Medicaid coverage waived so that Katie could live at home after having spent her first three years in a pediatric intensive care unit. A year later, the Department of Health and Human Services established options for state Medicaid programs known as the Katie Beckett waivers.

**Family Voices** is a national grassroots network of families and friends speaking on behalf of children with special health care needs.

## **MISSION:**

"The Family Voices mission is to improve health care delivery systems that serve children with special health care needs by exchanging information with and supporting the expertise of families throughout the country."

## **PROGRAM:**

Family Voices gives voice to children with special health care needs by ensuring that policymakers and the general public receive information and guidance from the families of these children. This national network was founded in 1992 in response to a presidential campaign that focused strongly on health care reform. Families of children with special health care needs believed that it was urgent that their children be considered in the development of national health policy. Many families and professionals knew that children with special health care needs would not receive the services they needed under health care reform initiatives, whether state or national, public or private, unless families and professionals actively participated in the dialogues and decisions about health systems.

Family Voices, a volunteer organization with more than thirteen thousand (13,000) members, began by word of mouth and with help from seed money from two professional partners, the Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs, and the Robert Wood Johnson Foundation. Although its focus is children with special health care needs and their families, Family Voices represents all children and families, because all children can at some point receive specialized services. Family Voices builds upon a network of one hundred twenty (120) volunteer state coordinators who represent all fifty (50) states and the District of Columbia. Coordinators inform and



work with state and local members around policies and issues affecting children's health. Ten regional coordinators (See page 45 to learn how to contact your regional coordinator) exchange federal, state and local information with members. A Board of Directors, which includes one member of the Family Voices staff, family members and professionals, moves the organization's mission forward. Family Voices shares information, resources, and family perspectives through a bi-monthly newsletter, teleconferences, fax alerts, bulletins and issue papers. Family Voices staff have developed expertise in health policy

issues that impact children with special health care needs and their families who are from different cultures. They provide extensive consultation on issues related to culturally competent care by linking groups who have particular knowledge and experience with other groups in need of this information.

Family Voices costs nothing to join and, as National Coordinator Julie Beckett says, “only asks that its members represent their own families and other families like them” in the discussion of and advocacy for children’s health care needs. All levels of advocacy are respected and represented, with a recognition that most families will participate at the community level.

**FUNDING:**

Family Voices’ funding comes from the Robert Wood Johnson Foundation, the Annie E. Casey Foundation, and the Federal Maternal and Child Health Bureau, Division for Children with Special Health Care Needs and Division for Child and Adolescent Health, as well as from individual donations.

*We do this for all children, not just for those with special health care needs.*  
Julie Beckett

**FAMILY VOICES STRATEGIC PLAN:**

Since 1995, Family Voices has been involved in an ongoing collaboration with Partnerships For Change (an MCHB project housed in the Department of Social Work at the University of Vermont) in the development and updating of a strategic plan. The purpose of the plan is to guide Family Voices’ decision-making through this time of rapid growth. At the Family Voices Training Conference in April, 1995 in Washington, D.C., focus group methodology was used to ask the audience, consisting of Family Voices State Coordinators and Family Voices members, to respond to the following question:

**What Do We Want Family Voices To Be Doing Over The Next Three Years?**

More than sixty members representing approximately forty states contributed their ideas. Analysis of the responses resulted in the creation of the strategic plan, which says:

**FAMILY VOICES WILL:**

- create a shared vision;
- work on the development of Family Voices state structure, capacity and mechanisms;
- improve internal and external communication and organizational structure through long range planning;
- provide outreach to all family members;
- provide outreach to hard-to-reach underserved populations;
- develop a coordinated training effort;
- collaborate with professional agencies in advocating for children with special health care needs.

As a result of these activities, Family Voices will impact policies at the local, state and national level.

## PARTNERSHIP LESSONS: FAMILY/PROFESSIONAL

*The family, we call them the experts, and they really are. They've got the frame of the puzzle and most of the pieces, except for the few very specific pieces that professionals can bring.*

Maggie Schwarz

**Listen to families and try to understand their experience:** Perhaps the most important advice that family members can give to professionals is to listen to families. Every family is unique, and if professionals want to help families, they must be willing to hear what they have to say. Maggie Schwarz advises professionals to “start where the family is. I don’t know where they are, so I wait until they tell me...I push paper and pen away, and we relate as human beings.” Openness to the family’s experience is essential, which may challenge professionals to recognize common human bonds. Josie Woll adds that everyone has experience in a family, which they can draw upon as professionals. “All professionals bring their family experience to their different disciplines, and I think that it is incredibly important that they use that experience and that wisdom to understand some of the processes that are going on with the families with whom they work.”

**Recognize and acknowledge families’ expertise and central role in the lives of their children:** Families are the experts on their children and the constants in their lives. Josie Woll cites Jeanette Chang, her family’s pediatrician, as an especially effective professional, because she not only recognized the family’s expertise, but demonstrated “eagerness to learn from their experience.”

### E X A M P L E

Josie’s family participated in the initial early intervention pilot program in Hawaii. Dr. Chang, interested in understanding their experience, “actively listened to our account of what we felt we had learned: how the program was helping Cass (our daughter), the staff’s relationships with her two brothers who would come with me, our sense of ‘okana’ (family) with the other families we’d met in the program, and so much more. As a result, she became an advocate for early intervention among her peers, encouraging them to use the program.”

**Recognize and respect the contributions of both family members and professionals:** As Maggie Schwarz says, “We each have our own bag of tricks that we’ve learned from experience, things that have worked, and we’re just sharing them with each other.” Once expertise has been shared, decisions rest with the family, including the child as much as possible. Josie describes how Dr. Chang empowered the family: “She gave us a lot of information, a lot of knowledge, so that Cass’s dad and I could make really informed choices about our daughter. There were life and death issues that we had to make decisions about. She gave us support all along the way, whether we agreed with her recommendations or not...and she ensured that Cass was always a part in medical decisions as much as possible.”

**Become partners with families:** Although families are often very skilled in advocating for themselves, the complexity of the systems and the sheer enormity of their family responsibilities mean that they may need professionals to join them in the advocacy role. Supporting the family’s position with insurers and

other professionals, or just being there for them at Individual Education Plan (IEP) or other meetings can help them to feel less overwhelmed.

More than advocacy, families may need a professional partner by their side to ease their journey through the system. Maggie Schwarz describes this role as acting as a “navigator, holding a flashlight for families to help them to negotiate the tunnels of the system.” She adds that a professional who has taken the time to get to know the child can help the family to communicate the child’s strengths and needs, so that specialists can take their evaluations “out of the vacuum and put them into a context,” a context that will ensure that recommendations make sense for the whole child.

As a social worker, Maggie feels that “one of the most empowering things I can do is give families little pieces of respite, take some of the stressors off them, even if they are little things...not because they are not capable of doing it themselves, but because they are tired, and they are carrying a lot.”

Another important role for professionals is that of supporting the family at the time that their child is diagnosed. Maggie reminds us that being in a room full of professionals who are “telling them what is wrong with their child” can be very intimidating for families, and that they may need preparation and support in order to maximize their ability to participate. She adds that when families are given diagnostic information about their children, they are often swept up in a “tidal wave” of thoughts and feelings. It may help them to know that a professional partner is aware of how painful it is, and will be there for them throughout the process of “adjusting, readjusting, adjusting and readjusting.”

**Engage fathers from the beginning as valued partners:** Bob Craig makes the point that the vast majority of professionals who work with children on a direct basis are women. He cites the example of a neuro-developmental training program he recently attended with his family where there were over seventy participants, but he and his son were the only two males present. He says that it is important for professionals to remember that this minority status can be intimidating to fathers. Also, it is not uncommon for fathers to be present at meetings about their children in which they feel invisible because the professionals neither make eye contact with them nor address questions to them. If the mother is present, she is often the one to whom information and questions are directed. For these reasons, Bob suggests that professionals “take a little special care to make fathers feel welcome in the process.” When professionals speak directly to all family members who are present, they are reinforcing the fact that they all have important roles with his child. “If you ask a father a question, even if he doesn’t know the answer, you have communicated a positive message.” He also recommends as much as possible, scheduling appointments at times when both par-



*If a father doesn't know who the professionals are, or understand the process and what they are trying to accomplish, he won't be engaged, and he won't be able to help.*

Bob Craig

ents can be present. When this is not possible, it helps a father to feel included if one of the professionals calls him with a report on the outcomes of the visit. Professionals can also send questions to fathers or ideas for projects (e.g., a specific physical exercise) that they can work on with their children. Following these suggestions may be more time-consuming for the professional than focusing on just one parent, but the benefits for the child can be extraordinary.

**Develop partnerships with many family members:** Bob Craig notes that, particularly in the preschool years, no professional can possibly spend enough time with a child to ensure that he or she makes real progress. He views professionals as advisors whose role is to counsel the family on what they should be working on with the child and how to work on it, while always listening to the

### **Suggestions for Professionals Working with Fathers and Families**

Fathers, whether married, separated, divorced or never married to their child's mother, need to be encouraged and supported in their roles as parents. A few examples of how to ensure fathers' and other family members' participation in work with professionals and systems include:

- Support the participation of fathers and other family members in the leadership of family organizations and state and national programs such as Title V programs.
- Find opportunities to reinforce the importance of the father's role.
- When you call a family on the phone and the father answers, talk to him rather than asking for the mother, even if she is the person with whom you usually have contact.
- In meetings, make sure to make eye contact with the father and ask for his insight.
- Audio or video tape (with parents' permission) meetings with professionals, because it gives the family member who is not present a way to be included without having to depend on the other parent's report.
- Change meeting schedules to accommodate parents' work schedules; offer early morning, lunch or evening appointments.
- Recognize that separation or divorce may create some difficulty in involving a parent who is non-custodial, and think about how to share information with both parents in a way that is respectful of all concerned.
- Recognize and understand the culture of the family and the family's own definition of "family" when learning about who should participate in the care of the child and in decision making around the child.





family's perspective. Bob advocates involving as many family members (siblings, grandparents, etc.) and friends as possible in this process. "If those who have routine, everyday contact with children with special health needs are engaged in helping them to reach their potential, it's almost as though they have the benefit of a full-time rehabilitation program."

**Create opportunities for family leadership:** Most parents of children with special health care needs do not aspire to be parent leaders. As Betsy Anderson says, "Most parents do not expect to become the parent of a child with a disability, but also most parents do not expect to become parent leaders. It would have been very presumptuous, and I think it simply did not occur to us. I was just a parent in there agitating for things, asking questions, kind of trying to get what I thought my kid and other kids needed." All of the Family Voices contributors identify ways in which professionals have supported them in becoming local, state and national parent leaders. Betsy Anderson particularly cites her son's pediatrician, Dr. Allen Crocker, of Children's Hospital in Boston. At a time when professionals and families operated in completely different worlds, Dr. Crocker invited Betsy to attend a meeting of the New England Regional Genetics Group. In Betsy's words, "The invitation itself was the major opportunity. However, he also did several other things, perhaps consciously, more likely just part of his personal style, that paved the way and that supported me in a very personal way. He introduced me to others at those meetings. He made sure that I knew who the other players were, and he created conversational openings that led to discussions of possible mutual endeavors. In those ambiguous social in-between times, he made sure that I had others to eat with. A key feature of Dr. Crocker's tactics – something that was a little heart-stopping before I came to be prepared for it – was that during a meeting he might suddenly call on me without notice, saying, 'Betsy, what do you think about that?' This was a phenomenal entre. When you

*In the most positive sense, once you start including families, there's no going back. It really enriches and changes your world forever.*

Allen Crocker

are new or a little uncertain, you may not know when the right time is to speak up or add a comment, or especially to offer a different or opposite perspective from what has just been said. He created that opportunity for me, in effect legitimizing the appropriateness of my participation. Sometimes he did this when there seemed to be a need for the 'lived experience' of families to be heard; other times it was when a prejudiced (or even outrageous) comment had been made. Dr. Crocker's interventions were done in such a straightforward way that the conversation, the discussion, was just naturally broadened to include families' experiences and comments. In terms of my professional development, it was a wonderful tutorial and helped me to develop skills and gain confidence in what has come to be a significant part of my life's work: collaboration with professionals on behalf of children and families."

### **How Professionals Can Support Families' Participation in Advocacy**

All of the Family Voices contributors had professional partners who contributed to their growth as parent leaders. Some ideas for professionals about how to support families' participation in advocacy are:

- Ensure family participation by consistently acknowledging their expertise and commitment and by working around their schedules and priorities.
- Know and understand the issues that are important to the family, and then help to facilitate their sharing of their perspectives in meetings and discussions, particularly when program managers and policy makers are present.
- Understand how a family's culture affects their participation, and help the professionals to adapt their behavior to be respectful of that culture.
- Help families to overcome barriers that are related to culture. For example, many people who are Native American are taught never to interrupt, which makes it difficult for them to be heard at meetings where there are many competing voices. Professionals can create openings for them.
- Invite family members to all meetings at which issues and policies that are relevant to them are being discussed, and encourage them to contribute their experiences. Often families are not even aware of these meetings, and they may not understand the important role that they can play.
- Take the time to introduce the family members to the professionals in the meeting, and to explain those professionals' roles in the group.
- Facilitate interactions between family members and professionals during social times such as lunch. Suggest that family members and professionals drive to meetings together. These kinds of interactions often support informal connections and increase feelings of partnership.
- While in a meeting or a conversation with professionals, include the family member in the discussion. Ask "What do you think about this?"



## **PARTNERSHIP LESSONS: PROFESSIONAL/INTERPROFESSIONAL**

### **Provide high quality services through coordination and a holistic view:**

A child with special health care needs is so much more than his or her disability, and a family is much more than its individual members. Being holistic means taking into consideration every aspect of a child and family's life and integrating the family's perspective into what is often a complex system involving many professionals from different disciplines. Communication among the professionals and family members and coordination of the system are essential. Josie Woll says that Jeanette Chang's effectiveness was related to the fact that she "naturally brought all of the health care and education professionals into the picture" and made the system flow. She "facilitated the information flow among the many specialists involved, always ensuring that we were included in the discussion as well as the decisions." For Dr. Chang, taking on the coordination role was the natural result of her commitment to high quality care. She saw the need, and assumed the responsibility to create a well-functioning team.

**Model collaboration for other professionals:** According to Josie Woll, "Dr. Chang's unique respect for our input and the integrity of our decisions (even when we did not agree with some of her recommendations) had significant influence on the other professional team members. They increasingly listened not only to us, but to each other, enabling solutions to be found that reflected a variety of perspectives." A professional who values and feels comfortable with collaboration will foster it by her/his leadership and example, by modeling teamwork and nurturing new members of the team as they come along.

**Improve child and family outcomes through family/interprofessional partnerships:** Among Bob Craig's family's experiences are "six years of pleasant IEP meetings and six years of totally successful IEPs," as a result of which their son, Bryan, is thriving in school. Bob firmly believes that "the more people, family members and professionals, you can get on the team, the more power you have and the better the outcome." He feels that if there is one person on the team who has a negative attitude, it is especially important to include lots of people with positive attitudes. Naysayers may not be won over in one meeting, but neither will they be able to dominate, and over time they may change their position. The sharing of expertise is also critical. Bob has witnessed parents, speech therapists, occupational therapists, physical therapists and teachers learning from each other and stimulating greater creativity through the exchange of ideas. "If you can keep turfism out of the issue and have everybody contribute, not only in their specialty but from their overall experience in working with children, the family, the child and the professionals all benefit."

**Practice cultural competence:** Trish Thomas cites two examples of professionals who were responsive to her Native American culture, although this way of working came more easily to one than the other. Trish describes herself at the time her son was diagnosed as "this quiet little Pueblo woman who never questioned authority and never made direct eye contact (because that is a cultural

*Our family's auditory/verbal therapist was a really good role model for me because she would pull me in. I was not very talkative at all, but she would do just that. We would be at a meeting and she would say to me, 'Tell them what you told me the other day,' and get me going. And once you got me going, you couldn't shut me up.*

Trish Thomas



thing with us).” Her son’s auditory/verbal therapist “pulled her right in as a partner.” This therapist brought Trish to meetings and encouraged her to tell her own story in her own way, to speak about what she knew. She modeled culturally competent behavior. “She was so attuned and culturally responsive that she got other people to be the same way.” Trish adds that this therapist realized and respected that Trish’s culture would not allow her to divulge certain things about their Native American health care, and she did not expect her to abandon her traditions. Together they “found a balance between western mainstream health care and our traditional health care.”

The Thomas family also worked with a physician who at first had difficulty with Trish because her “pace” was different from his, and because her flexible definition of family meant that various family members (father, aunts, siblings) would at times bring her son to his office. But the physician’s response was to “take the time to see who I was, that we are all people, that we are all individuals.” As a result of the family’s “educating him along,” he, and others in his office, now understand and accept these differences. However, Trish cautions that this is a process which takes time and effort. “We progress to this level over time.”

### **CLOSING THOUGHTS:**

Polly Arango reminds professionals that families are different, and that it is just this richness which makes working in the field of children with special health care needs so rewarding. However, in another sense, the differences are unimportant. “The level of education, the language, the economic status of the family are absolutely irrelevant,” because “what brings us together is our children.” These families are like all families in their love for and commitment to their children.

**The following is a list of Family Voices' ten regional coordinators:**

Please contact the Regional Coordinator in your area and begin a new family/professional partnership. Your Coordinator can give you more information about Family Voices activities in your state.

**Region I – Northeast:**

Connecticut, Maine,  
Massachusetts, New Hampshire,  
Rhode Island, Vermont

Barbara Popper  
31 Wilshire Park  
Needham, MA 02192  
617-482-2915

**Region II – Mid Atlantic:**

Delaware, District of Columbia,  
Maryland, New Jersey, New York,  
Pennsylvania

Heather Bennett McCabe  
3800 Burgundy Road  
Alexandria, VA 22303  
800-926-3544

**Region III – Atlantic:**

North Carolina, South Carolina,  
Virginia, West Virginia

Bob Craig  
Route 1, Box 412  
Farmington, WV 26571  
304-293-1495

**Region IV – Southeast:**

Alabama, Florida, Georgia,  
Louisiana, Mississippi, Tennessee

Cindy Arceneaux  
1546 Calvin Davis Circle  
Lawrenceville, GA 30243  
404-679-4814

**Region V – Central:**

Illinois, Indiana, Kentucky,  
Michigan, Ohio

Erica Cade  
19434 Rosemont  
Detroit, MI 48219  
313-532-1516

**Region VI – Southwest:**

Arizona, Arkansas, New Mexico,  
Oklahoma, Texas

Trish Thomas  
Box 1387  
Old Laguna, NM 87026  
505-552-9889

**Region VII – Northern Plains:**

Minnesota, North Dakota,  
South Dakota, Wisconsin

Ceci Shapland  
PACER Center  
4826 Chicago Avenue S  
Minneapolis, MN 55417  
612-827-2966

**Region VIII – Central Plains:**

Iowa, Kansas, Missouri, Nebraska

Position to be filled

**Region IX - Mountains:**

Colorado, Idaho, Montana, Nevada,  
Utah, Wyoming

Sally Maxey  
734 Jersey  
Denver, CO 80220  
303-399-6141

**Region X – West:**

Alaska, California, Hawaii, Oregon,  
Washington

Cassie Johnston  
6138 Waldon Drive SE  
Olympia, WA 98513  
206-588-1741

**National Office: Family Voices**

P.O. Box 769  
Algodones, NM 87001  
505-867-2368  
FAX: 505-867-6517



# **Peanut Butter & Jelly: A Culturally Sensitive, Community-Based Family Center in New Mexico**

### **CONTRIBUTORS:**

**Sylvia Ruiz** is the Director of the Bernalillo site, and a daughter of one of Peanut Butter & Jelly's (PB&J's) founders. Sylvia has been with PB&J for twenty years, and with her background in special education, has performed in many roles. The current focus of her work is networking and advocacy on behalf of both the agency and the community.

**Antionette Tellez-Humble** is the Early Childhood Coordinator at the Bernalillo site. She began six years ago as a classroom manager at PB&J and moved into an outreach counselor position before being promoted to her current responsibilities.

**Maida Trujillo** sought services at PB&J when she became a mother for the first time at the age of eighteen. Maida and her two boys, Joshua and Jerome, continue to benefit from the support and socialization offered by the preschool program, and Maida is very close to obtaining her GED.

**Stella Primavera-Stanz**, a mother who moved from Brooklyn to New Mexico, was especially vulnerable to the isolation often experienced by new parents. Her two children, Christopher and Jacqueline, have both experienced some medical problems. For Stella, the preschool program has provided a sense of belonging and a stimulating and nurturing atmosphere in which her children have "blossomed".

**Troy Martinez** is a Family Intervention Specialist with a social work background who works in PB&J's rural outreach program. Since he has always lived in rural Sandoval County, he grew up among the many cultures served by PB&J's Bernalillo site.

**Debbie Sanchez**, the Site Director of the Albuquerque core program, lives and works in the community in which she grew up, Albuquerque's South Valley. She first came to PB&J as a high school student to fulfill a community service requirement for a special curriculum. After graduation, she obtained a job as a classroom manager and continued to work her way up through the organization as she attended college part-time. Eighteen years later, she is a college graduate and the administrator of the core program in Albuquerque as well as Project ImPACT and Supported Living Services.

*Parenting is one of the most important things that we do in this life, and it's one of the least supported in this society. So in general, we could say that that is what PB&J does – supports parents.*

Sylvia Ruiz

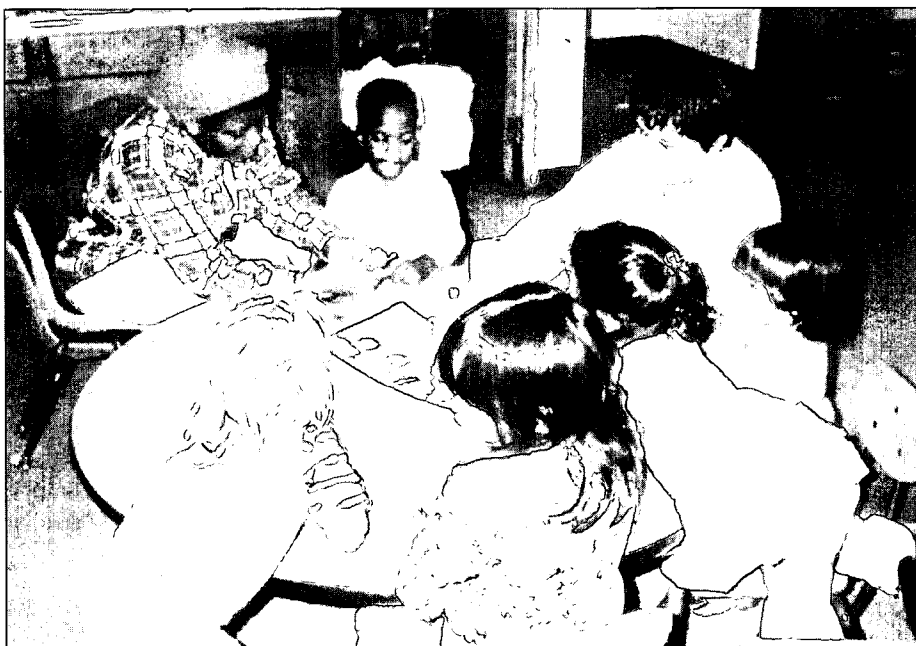
**Peanut Butter & Jelly (PB&J)** is a multi-program family center that provides services from two primary sites in Bernalillo and Sandoval Counties in New Mexico. The community served by PB&J is ethnically diverse and includes a major urban area (Albuquerque), fast-growing suburban towns and remote rural areas. PB&J works with families who for different reasons (e.g., developmental disabilities, medical problems, mental illness) are having difficulty with parenting and lack access to the resources they need to be successful. Many, but by no means all, of the families are court-ordered to receive services because of substantiated neglect or abuse of their children. Their mission statement emphasizes their philosophical base.

## **MISSION:**

“Within our community, many families are either at risk and/or exposed to events which may disrupt the healthy growth and development of children. When this occurs, the provision of family-based therapeutic intervention can improve family functioning and promote child development. Peanut Butter and Jelly Therapeutic Preschool serves high-risk families who lack the resources to help themselves.

“The thrust of the PB&J program is to strengthen all aspects of a child’s development, and to provide parents, as needed, the basic skills of daily living, effective parenting and self-advocacy. We believe that by focusing our efforts on the parent and the child as a system, as well as individually, we can take into account the powerful and unique reciprocal effect one has upon the behavior of the other.

“We believe that the enhancement of family members’ sense of self-worth and competency promotes each individual’s ability to develop as a capable and responsible member of our community.”



## PROGRAMS:

**PB&J's Core Classroom Program** is a therapeutic preschool that serves parents and children together. Components include: supervised therapeutic activities to strengthen parent-child communication, interaction and bonding, parenting education, child development education and activities, support groups and medical services.

**The Rural Outreach Program** provides adult and teen parenting classes and home-based therapeutic support to high-risk families in rural areas, including the checkerboard region of the seven Native American Pueblos in Sandoval County.

**The Home-based Services Program** provides intensive therapeutic services to families who are high-risk, particularly those who have had difficulty maintaining successful relationships with helping agencies. This project provides a flexible program, including parenting skills training and infant development services, in the context of nurturing, supportive relationships.

**The Supported Living Services** provides intensive home-based parenting and independent living skills training to adults with developmental disabilities and their children. Part of this program is a twelve-unit apartment complex where parents with developmental disabilities and their children can live in a safe, supported environment.

**PB&J's ImPACT Program** prepares parents who are in prison, their partners and children to function as families when the incarcerated person is released. The program provides individual support, facilitated visitation and psychoeducation-al groups at the prison and follow-up after the release.

**The Counseling Program** provides short-term individual, group and family therapy to prevent family problems from escalating and to generate solutions to enhance family functioning.

*It was good to get to talk to people and other moms. It was like, 'Oh, wow, everyone's got the same problems. It's not just me. Thank God, I'm normal.' ...I'm glad for Peanut Butter and Jelly. I don't know what I would do without it.*

Stella Primavera-Stanz

## HISTORY:

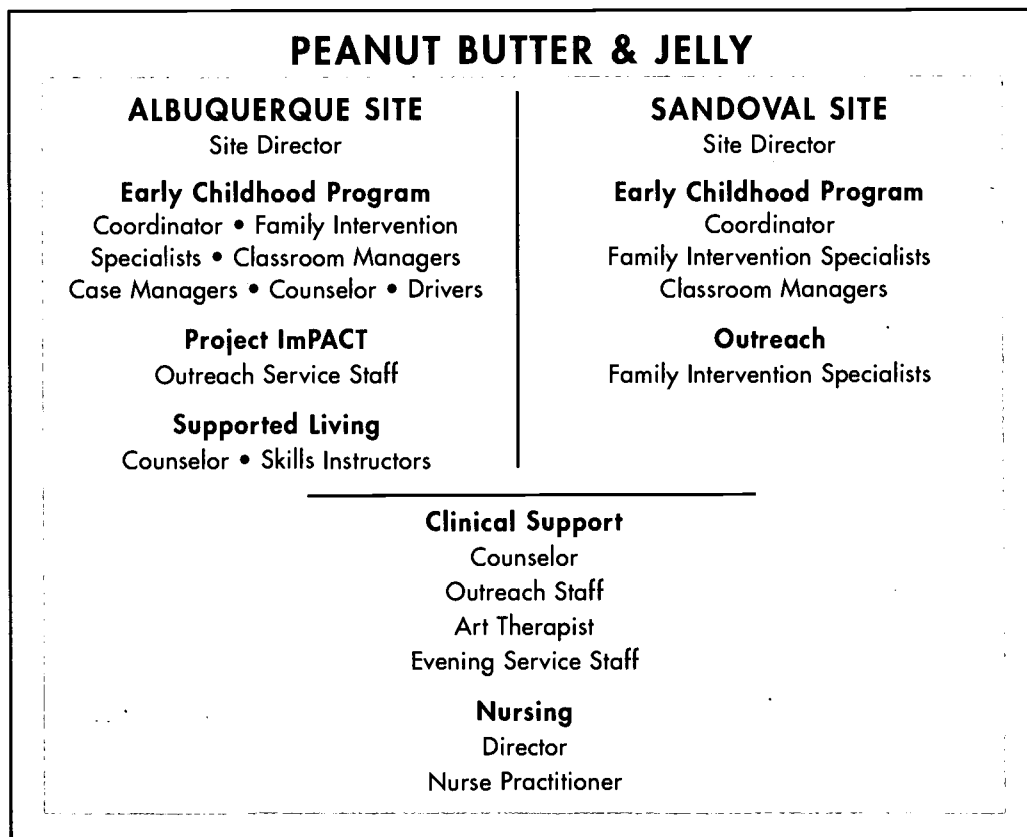
PB&J's history reflects its focus on the needs of families. Angie Vachio and Christine Ruiz Boyd, Sylvia's mother, were mental health counselors in the early seventies at the Mental Health Center at the University of New Mexico. Their clients were women with severe mental illnesses. In Sylvia's words, "In the seventies what mental health services (for this population) mainly consisted of was giving medication. And so my mom's job and Angie's job was to work with these moms, talk to them, counsel them and hopefully make their lives a little bit better. And they would come in once a week, talking and sharing their life stresses. They would get their shot of lithium or thorazine and leave." Angie and Christine became concerned, particularly about the women who were mothers who, again in Sylvia's words, would come in "talking and animated and certainly stressed, but functional" and would leave "doing the thorazine shuffle." They asked if they could visit some of these families and evaluate the impact on the children of their mothers' illnesses and treatment. Not surprisingly, what they learned was that the children's needs for stimulation and attention were not being met. When they



told their administrators that they believed it was vitally important to work with the whole family in these situations, a conflict ensued and both Angie and Christine lost their jobs. The two women then founded PB&J, which they staffed initially on a volunteer basis. The name was suggested by a child because the familiar sandwiches were served so often to staff and families during those early times of financial struggle. Twenty-five years later, Angie Vachio remains as the Executive Director and PB&J programs serve over a thousand families a day.

This history has become an integral part of PB&J's identity. All of the staff know the history and repeat it with pride when asked to describe their organization. As a story it embodies the agency's extraordinary commitment to families and forms the basis for an organizational culture that values empowerment and challenging the status quo.

This chart is a representation of the services provided at PB&J's two sites and includes the job titles of staff who provide those services.



## FUNDING:

PB&J's funding comes from seventeen public and private sources, including the state Departments of Health, Children, Youth and Families, and Corrections; Bernalillo and Sandoval Counties; Medicaid; United Way; and donations from individuals, corporations and businesses.

## PARTNERSHIP LESSONS: FAMILY/PROFESSIONAL

**Make commitment to children and families the foundation for all programs:** PB&J has earned its reputation as an organization that will do "whatever it takes" to help a parent or a child. As Polly Arango says, "They're known for being very practical about what they do, and 'just doing it.' They don't worry about how or why or funding, they just do it."



### E X A M P L E

Recently PB&J became reinvolved with a young man whom they had served years before, when he was four years old. At that time he had been diagnosed with fetal alcohol syndrome, and was already exhibiting behavioral problems. For example, every day he would stuff his pockets full of sugar from the coffee table and have to be "frisked" on his way out. His mother had become addicted to heroin and was in prison. His grandmother was raising him. The recent call came after he had been involved in an incident in high school that had resulted in his placement in a secure treatment facility and a subsequent suicide attempt. Debbie says, "We hadn't heard from him in years. We had no idea what he was up to." But the call came from the treatment facility, and Angie Vachio, the Executive Director, "immediately went up there and met with the people" and developed a plan whereby the young man would return home and commit to spending his mornings in special education classes and his afternoons at PB&J performing community service. Debbie tells the story: "He comes into my office...he sits down in the chair and puts his head down, and I reach out my hand to him right away and say, 'I know you don't remember me, but I remember you.' And he puts out his hand and I say, 'I really need to see your eyes, it's really important to me.' And so he picks up his hat a little and shows me his eyes and he's wearing shades. So I tell him to take them off...we have some serious stuff to talk about. I told him what we were going to do, and I said I expect you to be respectful, be a role model for all of these little kids. They're going to look up to you. None of this gang stuff, that's going to stop." David (not his real name) began in the kitchen, and at first required a great deal of supervision to stay on task. But soon staff could see his whole face, and he would say "good morning," do his kitchen job and take appropriate breaks. Eventually he began assisting a male teacher in a classroom of two year olds. "He was great with the kids, really great with the kids." Later he helped with the wilderness program, which provides summer camping experiences for parents and children. "He did the whole six weeks

of camp, loved it, and was a great helper, which really built up his self esteem. It was just amazing, the turnaround for this kid." PB&J received no funding for helping David, and they have no program that includes the services that they provided for him. There was a clear need. They saw hope where others would not have, and found a way to help.

**Plan services with children and families around their self-identified needs:** All of PB&J's services have been developed in response to the identified needs of families. Sylvia says, "We are out there in the community working with families, and we have addressed the needs that have arisen...Each one of those programs has begun because there was a family that came to us and said, 'This is what's happening in my family now. I need help with this.'"

#### E X A M P L E

The Supported Living program responds to a need that was identified over time, as staff observed that some parents, particularly those with developmental disabilities, were losing custody of their children despite the benefits of the preschool program. As Debbie Sanchez explains, "We were working with the families here, but we were finding that because of their cognitive limitations, these parents were not able to generalize or bridge that information that they were learning here to the environment that they were going home to." Their children were being separated from their parents not because they were abused, but because they were neglected, and much of the neglect was unintentional. The program began by providing intensive in-home education in parenting and daily living skills, and grew to include a 12 unit apartment complex, where parents and children could live together with even more consistent, daily support. These apartments serve those families who lack extended family or other natural support systems, and are intended to "create community for them, so that they can help each other." One indicator of their success with this goal is that some families that have left supported living housing have chosen to live as neighbors in another apartment complex and are maintaining mutually supportive relationships.



**Learn and work with each family's unique definition:** Debbie says, "When we talk about families, families are so unique these days that we'll work with whatever family is for that child. We're not going to exclude grandma or the neighbor down the road, or whatever. We're going to look at the whole picture and figure out what the roles are here...And parents tell you, if you really listen to their stories." PB&J staff believe that what they are teaching parents and children will be much more effective if other family members are also involved and aware.

E X A M P L E

As part of their commitment to inclusiveness, at the beginning of each school year, PB&J sponsors a "Grandparents Day." "We invite them to come and eat with their grandkids, and you should see. What a concept, to honor our grandparents! It is very powerful on both sides." All family members are encouraged to come to PB&J events and celebrations, included in Christmas food baskets, and offered support.

## **PARTNERSHIP LESSONS: PROFESSIONAL/INTERPROFESSIONAL**

**Create a welcoming environment:** Many of the families served by PB&J have experienced conflictual relationships with other agencies and have difficulty developing trust. PB&J staff know that they have to provide them with a different experience. One of the ways that PB&J creates a welcoming environment is by the appearance of their offices. The buildings blend into the neighborhoods where they are located and the furnishings and decorations reflect the cultures of the families they serve. In addition, staff communicate in numerous ways that the families are valued. Every morning they go out and greet the buses that carry the parents and children to the center. "The teachers, the direct staff, the work study students, it's part of their routine. We go out in the morning and bring them in, welcoming them." Every activity begins and ends with a meal. "They're hungry, and we can't begin to work on problems they have if they're hungry." Morning coffee is also an integral part of the program. Some staff at first questioned the productiveness of this socializing time, but Debbie says, "These are opportunities that they don't have in their daily life; they don't get a chance to go to the neighbor's and have a cup of coffee. They come from neighborhoods where they really don't talk to their neighbors. So we create those kinds of opportunities for them here. It's sort of a way to start their day just as we start ours." Debbie adds that probably the most important contributor to the warm and welcoming atmosphere at PB&J is the caring manner of the staff. "Our work is often very difficult, and in order to do it, we really have to care, not only about kids but about the parents. So I think that what leads to that warmth is the feeling among the staff that we're really here to help families no matter what their problems are. No matter what they've done, we truly are here to help them."

*Our job is creating  
that environment  
where families  
want to come.*

Sylvia Ruiz

**Address families' individual and changing needs through flexible programs and a flexible staff:** Another way to engage families is to respond to their

individual needs. At PB&J both the services themselves and the way that they are provided vary with the family's wants and needs. Although some parents, like Maida and Stella, feel immediately at home at PB&J, others need more time to be comfortable and accepting of services. Troy says, "We take all the time in the world for them. We invite them to come into our school, give them a tour. We try not to put them in an office, because we know how that can be somewhat intimidating. Sometimes we go sit outside. There are a variety of things that we do to help them feel comfortable..." Sylvia adds, "If the family is out there milking the cow, and you want to support the family, you go help them milk the cow. If that's when they need support, that's what you do, instead of bringing them into a little office for an hour a week." The curriculum for the preschool is individualized to address the needs of the parents and children who are involved at the time, and on any given day, the planned curriculum may be thrown out the window because something else is more important. Each family has an individualized plan which recognizes their culture and their strengths as well as their challenges, and may include a variety of services.

#### E X A M P L E

PB&J received a referral from Child Protective Services after the state agency had taken custody, in the hospital, of the newborn baby of a mother who was labeled as developmentally disabled. Years before, Debbie Sanchez had worked with the maternal grandparents of this baby and two of their children, ages 3 and 4. Debbie describes the family then: "They were here because the mom was mentally ill, very depressed. The dad was in a wheelchair – very poor family, lots of kids." Now the four year old was 18 and the mother of this new baby. PB&J began by working with the concrete concerns of Protective Services. Debbie spent hours with the young mother teaching her how to make formula. "I said 'bring what you are going to use, bring your bottles,' and we went into the kitchen and made a recipe on how you make formula." They cut out pictures and wrote down words that she could understand to make the step-by-step recipe. Then they practiced making bottles, over and over again until she could do it without a problem. They gave her a timer so that she would know approximately when to feed her son. Because of her motivation and PB&J's support, this mother regained custody of her baby when he was three months old. The family continued to benefit from PB&J programs until he was three and "graduated" to Head Start. He's now in public schools and according to Debbie, "a lovely little boy, really a joy." The mother has a partner, and with the help of Supported Living services is living and parenting her child independently of her family of origin. There have been no subsequent referrals to Protective Services.

**Address families' needs holistically through the collaborative efforts of an interdisciplinary team:** A family who receives services at PB&J has access to a number of professionals, including a nurse-practitioner, early childhood specialists, social workers, teachers and counselors. Once staff have had an opportunity to get to know the family, a client coordinator is assigned, usually based on

the age of the child and the expertise of the staff person, as well as whether services can be delivered at the center or home-based services are needed. Then the nurse-practitioner will generally do a medical screening and develop a plan to address any health-related issues. The family counselor will meet with the family informally in the classroom for additional assessment and rapport-building. The plan that is developed with the family includes the input of all of the professional disciplines, as well as the clerical staff and the bus driver. In the end, although most of the staff function as generalists in family intervention rather than within their professional specialties, all families benefit from the variety of knowledge and skills that is present in the agency.

**Create opportunities to work with parents and children together:** A recognition of the importance of working with parents and children together is part of PB&J's history and it remains central to their way of helping. The preschool program is built around the interactions of parents and children. It's an opportunity for parents to learn about their children's emotional and developmental needs and, through listening and observing, to enrich their repertoire of nurturing and stimulating behaviors. The success of the ImPACT program for parents who are incarcerated and their families is another living example of the power of families. The program brings families together in the prison who may not have shared a home for many years. PB&J set up a trailer on the prison grounds that "kind of looks like a home." They work with the incarcerated parents, providing classes on such topics as child abuse and neglect, appropriate discipline and child development. "We also work with the non-incarcerated parent and kids on the outside, and then we have trailer visits, where we bring the families together and work on family dynamics. They can be two to four hour visits, and they are always supervised by staff." Through this intervention family members learn about each other, as well as about parenting and family life. Project ImPACT has been extremely successful in preventing recidivism. Having been helped to be a functional part of a family when they are released seems to have created real change for these incarcerated men and women.

**Support parents as advocates for their children:** PB&J helps families with the preschool to school transition and prepares parents to be active participants in their child's education. In Debbie's words, "One of the things that we try to do is teach parents that you have a right to be in your child's classroom. If you get a letter saying that your child is acting up, make it your business to participate. Go in and see what's happening." PB&J also teaches parents, most of whom come from cultures in which respect for authority figures is very strong, to interact assertively with all of the systems with which they come into contact. Debbie says, "It's very rewarding to see families advocate for themselves and really be advocates for their children. And that's not something they're used to doing. They're very used to professionals telling them what to do; by all means you do not challenge. I mean, talking with the gas company can be very intimidating for them. And when they come to us, we say, 'You challenge every way. I don't care if it's your beautician, your teacher, your lawyer, you challenge; if you have ques-

*In four years we worked with one hundred inmates and only one ended up back in prison.*

Sylvia Ruiz

*We tend to think, and parents do too, that when the children are at school, they are the school's problem for six hours out of the day, and teachers say 'They're mine for six hours and not yours.' And I'm saying wait a minute, we've got to do this together.*

Debbie Sanchez

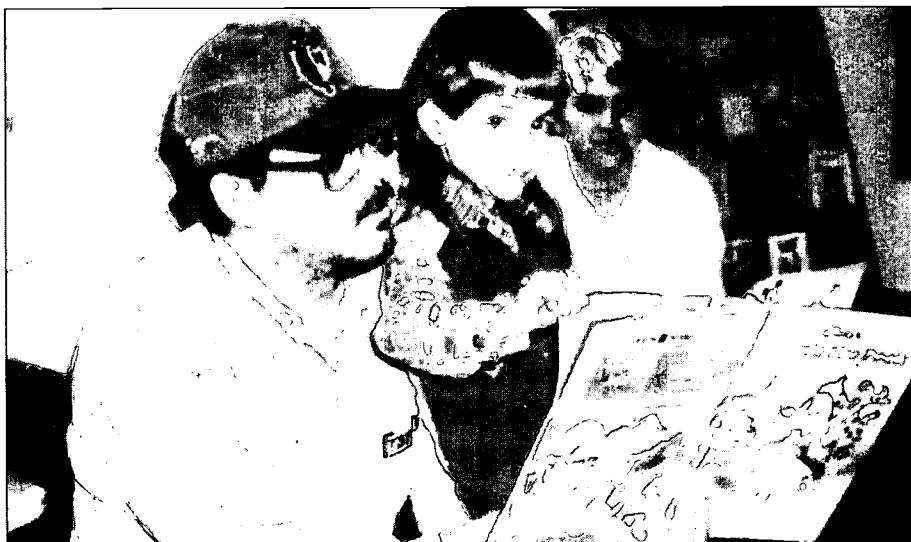


tions, you ask.” PB&J staff teach advocacy primarily through modeling. First they make the calls themselves in the presence of the parent. Then they may coach the parent on what to say and sit with her/him while she/he is making the call. This kind of support and encouragement continues until the family no longer wants or needs it. Maida and Stella are examples of parents who have integrated these skills and values. As Sylvia says, “These two women do a beautiful job of advocating for their families. I don’t think that their kids will ever get cheated in any way, shape or form, because these women, no matter what it takes, will be there for their children. They’ve learned to do that very well.”

**Empower and support families to become community activists:** PB&J staff keep the families with whom they work informed about political and policy issues that may affect them, and they have developed a number of strategies to support them in political or community action. This year they conducted a voter registration drive and worked with the League of Women Voters to provide the families with information so that they could make informed choices. On election day, staff and families went to the polling place together by bus. “When they came back on the bus from voting, they were just as lively as could be. And then if their person won, oh my God, the next day they were just overwhelmed. They won! My vote really did count!”

#### E X A M P L E

PB&J is currently working in partnership with a University of New Mexico professor to provide a class at their Albuquerque site about the political process. A group of twelve mothers, fathers and a few staff are gathering every Wednesday evening to learn about how to create bills and get them enacted. They have chosen three areas of importance to families: welfare reform, incarceration issues, and managed care; and are working on writing legislation to address their concerns. The response from the group members has been very enthusiastic. They are learning another way to make a difference for themselves, and for other families who are poor and so often lack a voice when decisions are made that affect them deeply.



At times PB&J has provided transportation for a busload of families to a legislative session so that they could express themselves about an issue of concern. Antionette says, "With kids running up and down the aisles, we get a lot of attention. So they are ready to hear us. They want to get us out of the way." It's also another great way for families to learn about their own power.

**Model advocacy on every level:** Since PB&J believes that advocating for the rights of families is part of their mission, they train all of their staff in advocacy skills and "practice what they preach" to families. As Sylvia says, "If no one is out there talking about this stuff, then nothing is going to change for families." PB&J staff are active in rural Sandoval County, where the Bernalillo site is located, to encourage the community to tackle issues, such as domestic violence, that have never been addressed before. In many school districts, they are involved in committees that are working on developing a vision for the schools and learning how to serve students better. For example, in Cuba, a community in the midst of a Navajo Reservation that is seventy-four miles from any of their sites, they participate in a committee that is focused on establishing a school-based clinic and day care center. The only day care center in the community has closed, which presents a hardship for students with children, and PB&J is determined to work with the school and be part of the solution.

The advocacy of PB&J's Executive Director, Angie Vachio, is an important model for staff and families. Debbie says: "Angie is the most dynamic woman and leader, not only of our program, but a leader for parents and kids. She participates in as many task forces and advocacy groups as she can to further what families need. She'll spend her time in Santa Fe advocating for money for WIC, or money for better benefits, issues which don't relate directly to the agency, but sure relate to our families. That's her vision, that she wants what's best for children and parents, and that she'll go in whatever direction she needs to make sure that families get heard."

**Serve a culturally diverse population through a culturally competent staff:** Everyone at PB&J understands and appreciates the importance of having a staff that, as much as possible, represents the various cultures of the families they serve. At the Albuquerque site, where many of the families are Mexican-American, Debbie acknowledges that having bilingual staff is helpful, but staff who share the culture are key. When families see a staff person who "kind of looks like them," there's a feeling of connection. It is much easier for them to believe that "maybe I can trust them; maybe they are going to help me." It's one less barrier. Because members of many ethnic and cultural minorities are more likely to be poor and less educated, and funding sources often require certain educational levels, recruitment is a challenge. PB&J routinely hires non-degreed community members as classroom managers, and "by tooth and nail, keeps a career ladder going" for them. "We bring people in and kind of nurture them along, give them time off to go to school, find out about alternative education." Debbie Sanchez is an excellent example of the benefits of this policy. As she says, when she started at PB&J as a junior in high school, "I had no clue how to get into college. I didn't even think I

*They have done so much, I think, to dis-  
abuse politicians of  
some of the myths  
about families who  
receive AFDC by  
bringing these won-  
derful families up to  
Santa Fe and having  
them give testimony.*

Polly Arango

*Decisions that are  
made on the  
Pueblos are not  
made without taking  
into consideration  
the next five  
generations. Before  
they make any  
decision, they think  
about how it's going  
to impact five  
generations. As  
opposed to the  
culture out here in  
our world, which is  
so 'right now.'*

Sylvia Ruiz

was going to college.” But she quickly realized that if she wanted to continue in the work she was growing to love, she needed a degree. Sylvia Ruiz helped her to find funding for her education, and now she’s a Site Director with invaluable expertise in the community she serves.

Although it is very important to have an ethnically and culturally diverse staff, it is equally important that every staff person practice in a culturally competent manner. PB&J staff can and do learn from coworkers who represent these cultures, but it is just as crucial that they learn from the families themselves. As Debbie says, “There’s no magic. It’s being respectful, respectful by not asking a lot of questions, but by observing. Because each family is different. It’s paying attention to the family, listening to what they’re telling you, instead of going in there full speed, perhaps way too fast.”

#### E X A M P L E

One of the things that Troy Martinez has learned is that you have to start slowly with the families you serve. “You go in there and you just sit there and talk. You don’t have to ask anything about what the situation is at first; you just get to know them. They have a word for it in the Hispanic community, it’s called ‘platica,’ to chat or converse. That’s how you build a relationship, you trusting them and their getting to trust you. You just talk about anything and everything.”

#### E X A M P L E

It took PB&J five years to get a referral from any of the Native American Pueblos. Sylvia believes that their long-term presence in the community and the consistency of their staff has helped. But she has also learned the importance of developing relationships with the Pueblo leaders. “Every year there’s a new governor and a new tribal council and I make a point of meeting them.” She begins with great respect by saying that she would like to come and make a presentation and ask their permission to serve their community. She has been consistently successful, and more recently some Pueblos have even requested services. Now PB&J staff are “members of the family,” invited to baptisms, feast days and other celebrations.

**Create an atmosphere of respect among staff which will support an atmosphere of respect for families:** Although it is not part of their formal orientation, Troy says that “from day one” employees realize that everyone on staff is considered to be equal and that no one is better than anyone else. Families sense the atmosphere of respect and trust, and have an opportunity to observe many interprofessional partnerships in action. Relationships with families mirror the mutual respect that characterizes relationships among staff.

**Build partnerships with schools:** Although their role as advocates for children and families sometimes puts them in conflict with school personnel, PB&J

has carefully nurtured relationships with the schools in the communities it serves. In addition to participating in the kinds of committees cited previously, they develop these relationships child by child, by consistently providing high quality services that the school experiences as helpful. Schools will often refer a parent who they feel is in need of support, or they will consult with PB&J staff about how to present the idea of family support to a parent. PB&J is always responsive to these requests. PB&J also provides services in the schools at times. They will go with a child and parent to the first few days of kindergarten to ease the transition. They provide an array of counseling services (developmental play, art therapy, group and family counseling) for children whom school counselors are no longer able to serve because of budget constraints. PB&J staff travel one hundred miles twice a week to work in a remote high school, to meet with parents and children.



At Bernalillo High School, Antionette and Troy make presentations in various classes on issues related to pregnancy and sexuality. They do this as a community service, at no charge to the school district. PB&J staff are continually looking for ways that they can partner with schools.

#### EXAMPLE

Every spring the Bernalillo site hosts a family day, an open house, at which the school system, PB&J and Public Health collaborate to do developmental screenings for area children. Public Health does the hearing screens, the school sends their occupational therapists, and PB&J staff perform the basic developmental screenings and take social histories where appropriate. This process allows the school system to identify children who may need early intervention, and also introduces parents to school personnel in a non-threatening environment, which tends to ease the home-to-school transition for families.

**Develop partnerships with the community:** The fact that PB&J is so much a part of the communities it serves helps to minimize the stigma of receiving services. One way to do this is to be responsive to community needs. "We have people who show up at the church, and the priest will send them over here, if they haven't eaten or maybe they need a better pair of shoes. So we'll see people who just walk in. We'll help them, give them coffee, and they'll head on their way."

PB&J helps to plan and implement community events, such as a "walk against abuse" and the "family day" referred to previously.

*We've been in the community for over ten years now, so I think we've built a rapport and a relationship with the schools. I think that they respect the work that we do as well as we respect the work that they do.*

Troy Martinez

#### EXAMPLE

Another significant event is PB&J's annual Thanksgiving dinner. Debbie says: "Every year we have a major celebration of thanks, to the community, to families, to social workers, anyone we work with. This year we went through twenty-six turkeys to feed probably eight hundred people. A lot of



neighbors came. We work closely with the high school down the road, so we invited the staff from there and the teachers and the kids, and they were here. And community leaders....it's our way of giving thanks to the community for supporting us." Debbie sees this event as also being helpful to families. "We can't work with these families and keep them to ourselves. We want them to be connected with all of the resources that are out there, because our job is not to keep them dependent on us, but to teach them to survive without us."

PB&J staff are also often invited to family and community events throughout the counties they serve. They always respond to these invitations, which they know honor them and their programs, and signify PB&J's acceptance as a natural and important part of families' lives.

## **PARTNERSHIP LESSONS: TRAINING/EDUCATION**

**Teach students about family/professional collaboration in the classroom and in field sites:** PB&J welcomes interns from many professions, including nursing, social work and medicine, work-study students and community service volunteers. Although implementing this philosophy of openness creates a lot of work for staff, they believe that teaching future professionals and citizens about the families they serve is critically important. Most students work in the classrooms. Student nurses are assigned families whom they support for a semester, both in the classroom and at home. Medical residents set up "office hours" in one of the classrooms or work with the staff nurse practitioner. All students are required to "process" the day's events with the teacher when their shifts are over. Being part of the programs at PB&J teaches interns about the kinds of things that trigger their reactivity, and gives them the opportunity to look at and acknowledge their own "hot issues" and biases. It also teaches them to be more sensitive to and less judgmental of families. As Debbie says, students learn "to be tolerant

*Community health, oh my gosh, take them out of the hospitals and let them work with the families, work with social issues.*

Debbie Sanchez

of people who don't always have it together, who may not present themselves well, who may not smell good. They learn how not to judge so quickly, and to take the time to look at the big picture before they jump in there and say this kid is being neglected."

**Provide training opportunities for all of the professionals together:**

Since PB&J staff believe that it is important for all of the professions to learn from each other, inservice days for all staff are part of their routine. At one such event this year, the agency's art therapist led all of the staff in a group art project. Troy says, "It was a fun thing, but we also got the point that different skills were needed to complete the activity." The finished product was put up in the preschool as a metaphor for how everyone needs to work together to accomplish the task.





# **PACER's Team Training on Transition**

## **A Statewide Partnership with Youth in Minnesota**

### **CONTRIBUTORS:**

**Ceci Shapland** is the Coordinator of Project Youth for the Parent Advocacy Coalition for Educational Rights (PACER) and the mother of three children, including Mac, a young man with a disability who is currently transitioning from school to adult life. Ceci has given presentations around the nation on promoting self-advocacy in youth with disabilities, sexuality for youth with disabilities and family/professional collaboration.

**Corey Jackson** is a 20 year old man with a learning disability who is a consultant with Project Youth. He attends the Transition Plus Program through St. Paul Public Schools. This program has assisted him in maintaining steady employment and in learning to make mature decisions concerning life goals. Prior to his involvement with this project, Corey acknowledges that he struggled both behaviorally and academically in school, and he adds, "I would sit around my house and watch basketball all day long, and not get up and go to my job." Now, in contrast: "I am using the energy that I used to use to try to hide my disability to do the right things for myself."



**PACER Center** is a coalition of organizations founded on the concept of Parents Helping Parents. Its focus is on serving the needs of children and adults with disabilities – physical, mental, learning and emotional – and their families. Located in Minneapolis, PACER offers programs for Minnesota parents, students and schools, and technical assistance to parent centers in other states.

## **MISSION:**

“PACER strives to improve and expand opportunities that enhance the quality of life for children and young adults with disabilities and their families.

“PACER brings together the efforts of families representing twenty disability organizations, and includes a large variety of programs geared toward serving every age group and disability, and which support both families and professionals. PACER is staffed primarily by parents of youth with disabilities and by persons with disabilities. PACER’s programs assist parents in becoming informed and effective representatives for their children in early childhood, school-age and vocational settings. Through knowledge about laws, resources and parents’ rights and responsibilities, families are better equipped to work with agencies to obtain appropriate services for their sons and daughters.”

## **PROGRAMS:**

**Project Youth** is the component of PACER that forms partnerships with families, state agencies and professionals to focus on the needs of adolescents (ages 12-21) with disabilities and their families. For these youth and their families, the transition to adulthood is filled with opportunities and challenges. As Ceci says, “Transition is about discovery. It is about finding self identity, moving from home, learning about personal health care issues, developing relationships, being involved in recreational activities, and standing up for oneself.” Transition is a time when active collaboration among families, service agencies and the health community is especially important in order to ensure that adolescents are sufficiently equipped to advocate for themselves as adults. Project Youth’s goals reflect PACER’s philosophy that the mutual contributions of families and professionals are necessary to produce positive outcomes for youth with disabilities:

- To provide information and support for youth with disabilities and chronic illness in transition;
- To provide information and support for families of youth with disabilities or chronic illness; and
- To work collaboratively with state and community professionals serving youth with disabilities to provide family-centered transition services.

**Team Training on Transition for Teens with Disabilities, Their Parents and Professionals** is part of PACER’s Project Youth Program and an example of the organization’s commitment to nurturing partnerships. This project grew out

*Talking to you guys  
and being part of  
the team training  
really makes me  
feel good...for you  
to understand  
where I am coming  
from, what I am  
thinking about.*

Corey Jackson

of a recognition that although Minnesota had long ago mandated that schools work with students with special needs on planning for their lives after secondary education, the needs of these young people were not being met. Unemployment for youth with disabilities continued to be very high, and few were going on to further education. When the state Interagency on Transition looked at this issue, they identified lack of interagency coordination and follow through on Individual Education Plans (IEPs) as central to the problem. The state Department of Education convened a collaborative group of parents and school personnel, who developed a creative solution, the Team Training on Transition.

The goal of the Team Training is to train family members, youth and professionals to form transition teams led by the teens themselves and to develop transition plans that are based on the hopes, dreams and strengths of the teen. The training is carried out by a team, consisting of a teen, at least one parent, an educator and any other professional (e.g., physician, nurse, social worker, therapist) or community member (e.g., employer) who is critical to the transition. The training team talks about its own real life experiences with transition planning.

The trainees also come to the training as teams, and part of the training is actually working together to begin to create an IEP that is stated in terms of the student's goals, tasks and commitment. For example, an IEP task for the student could be, "I will call two area colleges to learn about entrance requirements."

Transition plans that are developed in this collaborative way are likely to succeed because students are invested in them and because they are supported by trained, committed teams. Corey says: "As adults we all have challenges in our lives that we have to overcome. I think that with the right transition plan, and by sitting down with the people that you really care about and who really love you to help you through things, it can get done." Besides developing the skills to create effective transition plans, professionals who attend the team training gain a better understanding of student and family perspectives and begin to acknowledge the importance of integrating them into planning. As one professional participant said, "People with disabilities have goals of their own and they don't need anyone else to make them up for them."

*Teamwork is important. It helps make the process more enjoyable and easier when help is forthcoming.*

Professional participant  
in team training

*...and the wonderful benefit of having real teams as trainers is that it isn't a script; it is real. We talk about real problems, real everyday happenings.*

Ceci Shapland

In addition to Project Youth and its Team Training on Transition, PACER has numerous other programs which provide diverse services to people with disabilities and their families. The following is a sample of some of the other PACER programs that support youth with disabilities in their transition to adulthood:

**Project PRIDE:** This project informs and trains persons with disabilities, their family members, advocates and professionals about how to apply the Rehabilitation Act and other legislation such as the Americans with Disabilities Act (ADA) to meet their transition, vocational and rehabilitation needs.

**Transition and Natural Supports in the Workplace:** This project engages co-workers and supervisors as partners to provide on-the-job support to persons with moderate and severe disabilities. Job selection is based on prior

*I made a greater commitment to my transition plan and being successful. I realized that I am an important person and can be successful if I put my mind to it.*  
Corey Jackson

career planning, and skills useful for succeeding in supported employment are identified for inclusion in high school programming.

**Parents Helping Parents Program:** This project provides information and training to parents concerning their rights under Individuals with Disabilities Education Act (IDEA). Staff provides individual assistance, often participating in IEP meetings to help guarantee that the plan truly focuses on the youth.

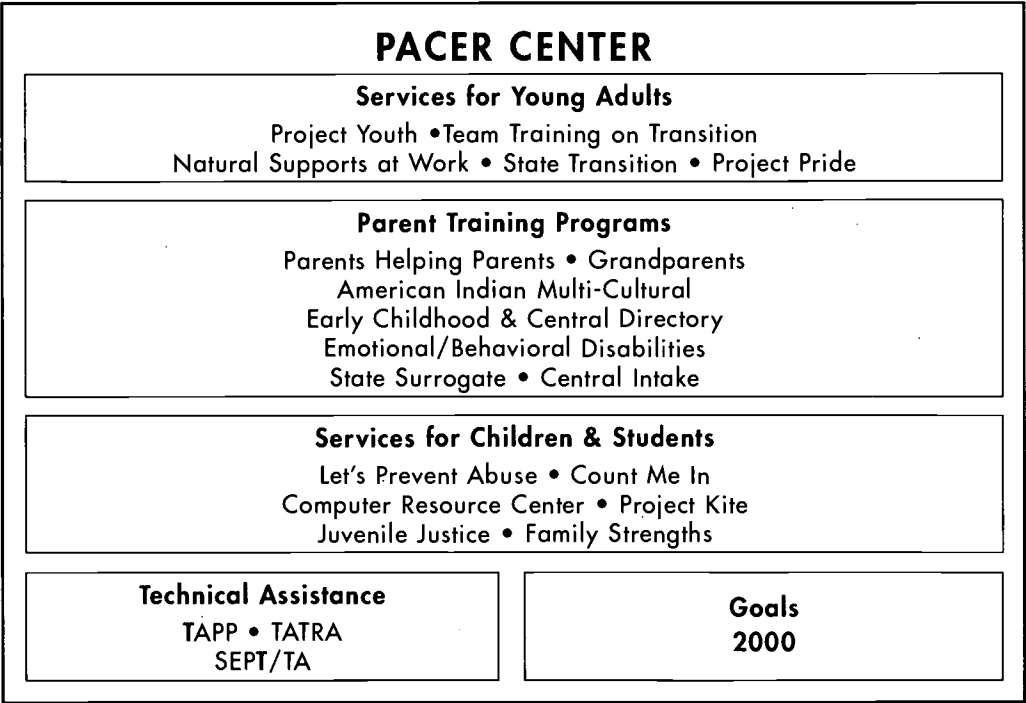
**Project for Parents of Children with Emotional and Behavioral Disorders (EBD):** This project offers individual assistance on education, social services, mental health and corrections issues, and provides workshops and written materials to parents of youth with EBD.

**Juvenile Justice Training Program:** This project trains professionals who work with youth whose disabilities may place them at risk for involvement with the justice system.

**Supported Employment, Parents, Transition and Technical Assistance (SEPT/TA):** This national project assists groups who train parents about the needs of youth who seek to work and live in the community.

**Technical Assistance on Training about the Rehabilitation Act (TATRA):** This program serves six regional projects that train individuals with disabilities and their families about the services and rights available under the Rehabilitation Act.

This chart represents some of PACER’s diverse programs, and demonstrates that services for youth are distributed throughout the organizational structure.



## FUNDING:

PACER is funded by grants from the U.S. Departments of Education, Labor and Health & Human Services and other sources, as well as by contributions from foundations, corporations and individuals.

## PARTNERSHIP LESSONS: FAMILY/PROFESSIONAL

**Listen to families and understand their changing needs:** Transition is a difficult time for families, teens and professionals. Ceci acknowledges that sometimes families are tired, and they may not show up for meetings. They may be suffering burn-out; they may be overprotective. But it is important that professionals consider the possibility that families are going through a grieving process. During transition, families may once again come face to face with the extent of their child's disabilities, and grieve all over again. Listening to the family's perspective is particularly important during times of transition, when stress is high and the need for planning and for everyone involved to work together is so pressing. In Ceci's words, "I think the people, the professionals, who probably helped me the most throughout the process of parenting Mac were the people that listened to me. And maybe sometimes they couldn't correct the problem, but they listened to what I had to say. I can't tell you how something like that just cuts the stress right in half, because all of a sudden we are kind of in this together."

**Include youth as collaborators in providing services to youth:** PACER involves youth in all of their transition-related programs. They are the experts on their own lives and must be at the center of any plans that are made. In addition, PACER employs youth as trainers and consultants, which enhances the effectiveness of their programs and gives the youth the experience of being valued and successful. It also provides the mentors and role models that are so important for all youth, but particularly for those with disabilities. PACER encourages and empowers youth to be advocates for the programs that help them.



*I am often asked to speak as the parent of a child with disabilities, but what is really wonderful is that now we are moving that one step further and having young people as part of the group and part of the presentation.*

Ceci Shapland

## E X A M P L E

PACER recently piloted a program which placed a young man with a disability in area high schools to provide ongoing mentoring for other youth with special needs. His work included holding weekly discussion groups on issues related to transition planning, as well as meeting individually with students to help them to identify goals for their transition plans. In addition to promoting self-advocacy for individual youth, this project resulted in the development of a game, "Transition Trek," which allows students to explore their hopes and dreams for transition through the familiar and comfortable medium of play. This game can be played with other students in school settings or at home with family members.

**Ask youth what they need:** All PACER programs empower youths by placing them at the center of planning for transition. However, staff felt that it was important to assess and document the transition-related needs of a broader spectrum of youth with chronic illnesses or disabilities throughout Minnesota. Project Youth staff, in collaboration with the Title V program, Minnesota Children with Special Needs, developed and implemented the first state survey of youth. Prior to this assessment, all program development had been done without information from youth about their needs. Information essential to professionals, policy makers and program planners was obtained through the survey. For example, it was learned that although health professionals tend to emphasize the positive when talking with youth with disabilities, young people want more information about the realities of their conditions. They need to talk about their fears as well as their hopes. What should I do in case of an emergency? What happens if I get worse? How am I going to pay for medical services? It is important that health professionals recognize that youth need this kind of information/instruction if they are to feel ready to be responsible for themselves.

Another striking finding was that when these youth were asked who they would talk to about such issues as alcohol use, hurting themselves or anger, the majority answered "no one." This implies that they are lacking the peer support that is so critical for all youth in navigating the perils of adolescence. All professionals who are involved with youth with special health needs should be aware of the social isolation that they may feel. Professionals can help to build and strengthen natural networks, and wherever possible they should present themselves as supportive, interested listeners.

**Employ family/professional partnerships to assist youth and families in implementing a family-centered approach:** In response to a clear need, Project Youth developed the unique position of family resource coordinator. This coordinator responds to the needs of individual youth and families as they go through the transition planning process. She/he attends IEP meetings with youth and their families and models a youth/family-centered approach for all participants. The coordinator keeps the focus on the goals and dreams of the youth, which dra-





matically changes the tone of these often intense meetings. The result is an increase in creative problem-solving among team members and transition plans that truly reflect the youth's vision of his/her future. Sometimes it takes just one person saying it is possible to help everyone to see the potential.

## E X A M P L E

Bill is fifteen and lives in rural Minnesota. He is labeled as borderline mentally retarded and is coping with severe mental health issues. For the last several years, although Bill worked diligently on academics in his high school program, he was able to achieve only limited success. His parents, who assisted him in doing homework for three hours every night, and observed his growing frustration, questioned the benefits of this all-academic program for their son. His mother requested that the school look at different programming, but they said that they did not have anything else to offer Bill. In frustration, she called Project Youth's family resource coordinator. When the coordinator helped the family to explore Bill's hopes and dreams, one of the things they learned was that he had an interest in the health field. The next step was to call an IEP meeting. The coordinator consulted with school personnel before the meeting to set the stage for coming together to creatively brainstorm various ideas for Bill. She helped the IEP team to realize that anything was possible if they worked together. Eventually they came up with a whole new IEP that focused on providing Bill with opportunities to work in the community and receive school credit. This was something that had never been done in the school district before, but the team members decided to take the risk and agreed to problem-solve as situations arose. Although finding the right placement required some teamwork, Bill is now very happily working in a nursing home. He feels good about himself and his education.

*All you need are one or two people at the table who have a positive attitude, who are creative and willing to try something new, and they can bring the others along.*

Ceci Shapland

## PARTNERSHIP LESSONS: PROFESSIONAL/INTERPROFESSIONAL

**Redefine professional roles based on the needs of the youth and family:** Professionals need to extend themselves to families and sometimes go beyond their job descriptions to reach out person to person. Corey identifies, as a turning point in his life, a summer night when he skipped work and missed an appointment with his case manager, Ron. Rather than giving up on Corey, Ron tracked him down and let him know how upset he was. In Corey's words, "My case manager came to meet me at my job site (I was working at a recreation center at the time) and I wasn't there. I got a call from him a couple of hours later and believe me, he wasn't too happy. I had an earful. He was very, very upset. I think that after how upset he was and hearing from my parents, I woke up. I think that made me realize I have to do it for myself." The obvious caring and genuine concern of this man helped to make the difference for Corey.

**Use a family-centered approach to support interprofessional collaboration:** A focus on the family's wants and needs can help professionals to over-

come barriers to working together effectively. If everyone is focused on the same goal, then the question becomes “How do we get there?” At that point the planning process becomes much less about professional roles and agency functions and more about using everyone’s skills and talents to meet the needs of the family and youth. Ceci describes the experience of PACER staff: “Oftentimes we will start meetings with letting the young person talk about their hopes and dreams and getting people focused on not whose duty it is to do what, but looking at the outcome. This is where we want to go...And it’s hard to get someone to disagree with wanting the young person to be a success and to have a job. So if we all agree on that, then what can we do to make that happen?”

**Work from a strengths perspective:** Parents report that professionals who are trained in the area of disabilities sometimes have a stereotypic picture of a child’s capabilities. Effective professionals focus on what children and youth can do, and on finding different ways for them to accomplish the things that are difficult. As Ceci says, “Focusing on the strengths of the child...is especially important as it relates to transition. You know, everyone has been trying to fix the child for about fourteen or fifteen years, and he’s not going to get fixed, so what do we need to do now? How do we need to work with what this young person can do, and not what he can’t do?”

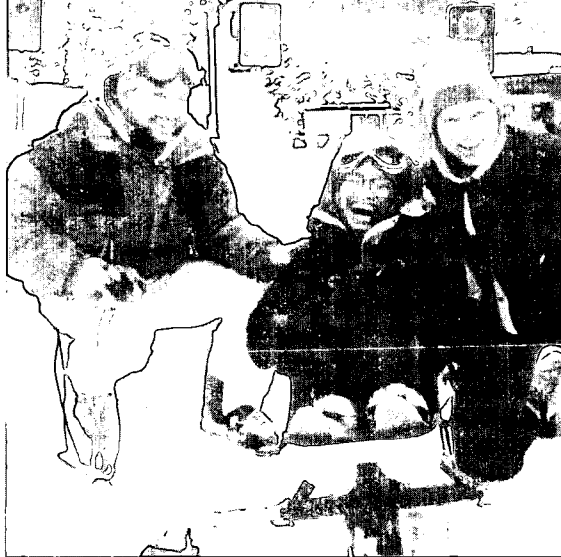
*Bringing in people who may not be bogged down with a lot of past knowledge...brings fresh new insights. If they say ‘I know Mac is really good at this,’ or ‘I know Mac really likes that,’ it helps.*  
Ceci Shapland

**Find non-traditional partners:** Parents suggest that including people who would not traditionally participate on the team can bring a fresh perspective. Examples are employers, other community members or extended family who may know and see the child or youth in a different way. Additional perspectives can help to identify strengths and interests that would otherwise be missed.

**Employ flexibility and creativity in developing a vision, defining roles and looking for funding to ensure effective problem-solving:** Most human problems do not fit into neat boxes or have tidy solutions. Transition can be particularly difficult for professionals because needs are so complex and plans look very different for each young person. Sometimes solutions are rejected because “We don’t have a program that does that.” If a youth’s needs do not match what existing programs are offering, that is a signal to begin brainstorming and looking beyond traditional boundaries. Resources that fit the young person can and must be developed.

**Develop cultural competence to provide individualized transition services:** Transition and transition services have different meanings for different cultures. For PACER staff, the first step is trying to learn about those differences so that they can provide meaningful services. They work hard to hire a multicultural staff and then ask that staff to talk with the families in their communities to learn about their experiences. The essential perspectives that are gained are then shared with other staff. For example, there is a large Southeast Asian community in the Minneapolis area. The idea of moving away from home as a transition goal is at variance with cultural traditions in many families, where extended families often live together throughout the life cycle. As Ceci says, “They define independence totally differently.” Transition has to be reconceptualized according to cultural norms. PACER staff have also adjusted their ways of working to be more

culturally sensitive. They have learned that delivering services through one-to-one home visits is more welcome than bringing families together in groups. PACER's philosophy of always asking the youth what they want has had to be adapted to respect cultures in which the parents are always consulted first. PACER is also producing an audiotape about transition in the Hmong language which incorporates what they have learned about the Hmong culture. In addition to home visits, it is felt that these families will appreciate information which they can absorb in privacy and at their own pace. PACER's commitment to cultural competence means that they are also providing training on how to work with Southeast Asian families to as many professionals as possible. Educators and health professionals are particularly benefitting from this sharing of knowledge.



## **PARTNERSHIP LESSONS: TRAINING/EDUCATION**

**Find family partners to participate in training:** PACER provides extensive training and education for professionals. One program trains pediatric residents by having them visit the homes of families. In addition, a family member from the agency provides direct training to the physicians about the needs of youth in transition, what the families are going through and how to work together. Many times trainings are done by family/professional teams who can model collaborative relationships.

**Create shifts in professionals' ways of thinking through training that models and teaches about collaboration:** When educating physicians and other professionals, PACER trainers emphasize the importance of being aware of the other people who are in this young person's life: family members, friends, community members and professionals. Although many professions do not include this kind of thinking in their preservice education, a creative, complete transition plan requires the input and expertise of everyone who has a piece of the picture. Transition plans that work must have all involved professionals committed to their success. Family and interprofessional collaboration can and should be presented in a positive light, not as another professional requirement, but as the right thing to do, a key to enhanced effectiveness and the most enjoyable, energizing way to work.

**Accept that attitudes change slowly:** PACER trainers often sense resistance both to their presence and to their message, because it is new, different and challenging at times. It is hard for professionals to share power when they have been trained to believe that they "know better." But family members who, as individuals and as trainers, talk with honesty and intensity about their experiences do change minds and hearts, a little bit at a time.

*As a parent advocate/trainer, I often walk into a room where people are thinking, 'What are you here for?' But when I walk out, their attitudes are a little bit better.*

Ceci Shapland



# **Project Unity: Family Empowerment and Community Renewal in Texas**

### **CONTRIBUTORS:**

**Jeannie Heller** is Project Unity's Director/Facilitator as well as the Coordinator of the Parent Education Partnership Program of the Bryan Independent School District. Jeannie is a social worker and the mother of six children, one of whom has recently been diagnosed as learning disabled.

**Jaslin Evette Smith** is a twenty-five year old mother who with her husband is parenting three young children. Jaslin describes herself as having been abused and neglected as a child, and when her first daughter was born, she realized that she needed to look for different models of parenting. Although she had been a very successful high school student and many people were urging her to go on to college, Jaslin decided to "concentrate on becoming a mother" to her baby so that "the things that happened to me cannot happen to her." This reaching out was the beginning of a journey toward self-esteem and learning to use her talents to advocate for herself and others. Jaslin is currently a staff member of Project Unity and an activist in Community Voices, a grassroots organization of neighborhood residents which identifies community needs and mobilizes resources to address them.

**Project Unity** is a local, collaborative partnership between and among agencies, professionals and community members in Bryan and College Station, Texas.

## **MISSION:**

"Project Unity's mission is to increase the abilities of families to successfully nurture their children by accessing resources across education, health and human service professions. With a shared belief in the importance of prevention, Project Unity focuses on the whole family and coordinates the efforts of community agencies seeking to strengthen and support families."

## **PROGRAMS:**

Project Unity comprises three collaborative groups and a Family Center:

The **Children's Partnership Board** (CPB) consists of more than one hundred members representing forty-five agencies (see appendix p.133) which serve children and families in the Bryan/College Station area. These agencies, which together form Project Unity's integrated service delivery system, meet quarterly for information-sharing, problem-solving, training and team-building.

The **InterAgency Coalition**, a more broad-based group than the Children's Partnership Board, includes agency executives and representatives from city government, school districts, the criminal justice system, the university, the medical community, and churches and civic groups (see appendix p.134). The Coalition focuses on enhancing collaboration on all levels in the community. It supports the activities of the CPB and the Family Center, as well as efforts that involve the wider community. An example is the Community Plunge, a day-long event which brings political and civic leaders into poor neighborhoods and introduces them to some of the realities that are facing families.

**Community Voices**, an organization of residents of neighborhoods served by Project Unity, meets weekly to provide leadership to the community and guidance to Project Unity programs. They have conducted a needs assessment and trained local leaders to develop community activism and to recognize and respond to the priorities of the residents.

The **Family Center** is both a community center and a place where neighborhood residents can conveniently access integrated services. Forty-five different agencies provide services from this one neighborhood site, and a host of recreational, educational and civic activities are available. The Mobile Unit of the Family Center carries representatives from health and human service agencies into the areas where they are most needed. On any given day, the van is staffed according to the needs that have been identified in a particular neighborhood, and many different agencies may be represented.

## **E X A M P L E**

After having learned of a neighborhood at high risk for HIV and tuberculosis, the Family Center's program manager enlisted the coordinated efforts of the County Health Department, an AIDS service agency and a regional

*I do believe that oftentimes we professionals give up way too soon on the parents and the family. I really do believe that they have so many strengths that they can bring to the family unit. They just need a little bit of support, a little bit of help.*

Jeannie Heller

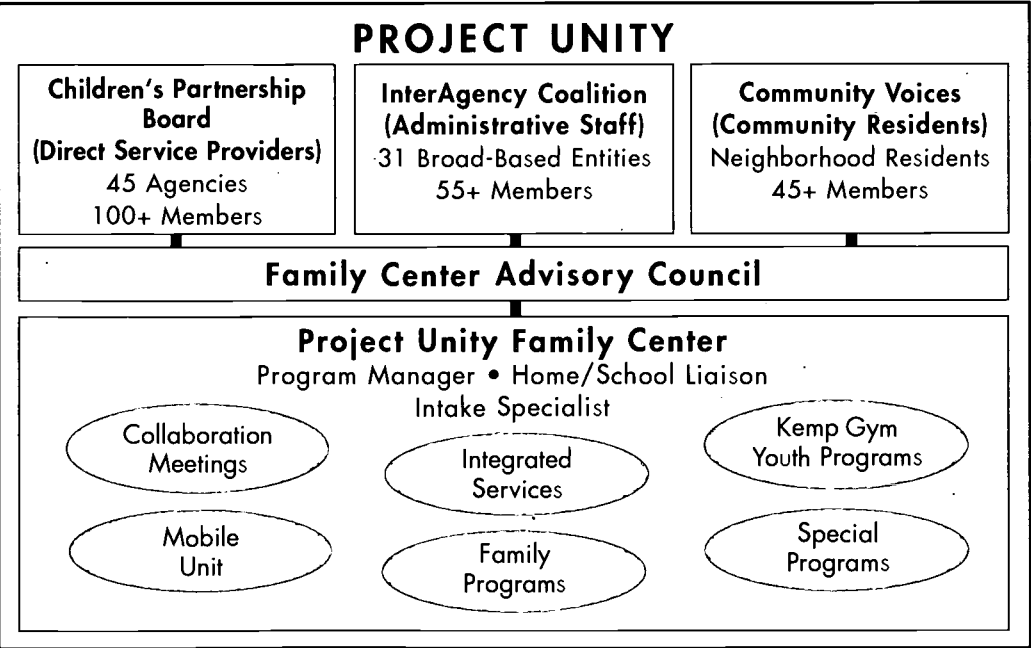
medical center to address this problem. The agencies agreed in advance to share the cost of the screenings and the necessary follow up care. In preparation for the Mobile Unit's visit, Project Unity staff passed out flyers and met individually with neighborhood residents to explain the services. On the appointed day, a team from the Health Department, AIDS Services and the Family Center went into the neighborhood and provided screening and counseling related to HIV and tuberculosis. In addition, Project Unity staff assessed the need for other services for a number of families and began the process of connecting them with CPB's integrated system.

Project Unity serves the ethnically diverse Bryan/College Station area, where 53% of the population was classified as low income or very low income by the 1990 census. Some of the problems that neighborhood residents identify are: drugs, break-ins, prostitution, gang activity, fighting in the streets, excessive garbage, lack of medical care, snakes and rats.

**FUNDING:**

Initial financial support for the Children's Partnership Board was obtained through a grant from the Danforth Foundation in 1992. Funding from the Texas Department of Protective and Regulatory Services enabled the Children's Partnership Board to begin to provide services as part of Project Unity. The funding base has expanded to include the following partners: Bryan Independent School District, St. Joseph Regional Health Center, City of Bryan, Brazos Food Bank, the Junior League of Bryan/College Station, the Norton Company, Children's Miracle Network, Columbia Medical Center and private donors.

This chart represents the relationships among the various entities that comprise Project Unity, and demonstrates its collaborative nature.





## PARTNERSHIP LESSONS: FAMILY/PROFESSIONAL

**Believe in families and focus on their strengths:** It is easy for professionals working with families coping with complex problems in multi-problem neighborhoods to become as discouraged and overwhelmed as the communities they are serving. The Family Center provides daily, living examples of what families struggling under the most difficult circumstances can accomplish with the appropriate support and encouragement.

### E X A M P L E

*Being a community voice, being a parent, being a member of Project Unity, it just fits, and I know that this is what I need to do with my life. And I thank God for it.*

Jaslin Smith

Jaslin says, "...So through the months, Jeannie taught me how to be a parent. It was okay to love my daughter. It was okay to encourage her creativity and growth and to look for signs of development. She gave me all of these packets of information (from the Parents as Teachers Curriculum\*). And she also (I didn't realize it until this past year) empowered me so that when my daughter became school age and got into school, I would not just settle for anything with her education. That I would know when something was wrong and have the power to fix it, and that I would not automatically side with the school and say okay, she has this problem or that problem. Because it isn't always the child..."

As an adult, Jaslin sought help for depression. "I contacted Family Outreach, and another messenger of hope came into my life. Jane showed me how to take care of myself as a parent, not just take care of my kid. You can buy yourself a pair of shoes without feeling guilty. You can take yourself to lunch sometimes, this kind of thing. So she and Jeannie kind of started to pull me out of my shell." Jaslin returned to college, and now is employed full time at the Family Center. "Through it all, I have healed. I'm okay now. When you think of everything I had to go through, I am quite a success story. And there's better to come."

*E-mail is great, faxes are great, but they don't create relationships that are based on trust and doing the things that need to be done. So I knew that we had to stop what we were doing and sit in a room together.*

Jeannie Heller

## PARTNERSHIP LESSONS: PROFESSIONAL/INTERPROFESSIONAL

**Begin collaborative efforts by finding a common purpose:** The relationships among the agencies that made up the original Children's Partnership Board were characterized by a lack of cooperation and trust. Jeannie put it simply: "We didn't like each other." Since she knew that time together was essential if real change was to occur, all participants were required to agree to meet face-to-face for a whole day every two months. They talked about why they didn't like each other, why there were tensions. They said the things that needed to be said before they could work together. After a few of these long meetings, the participants learned that the differences between them were not consequential and that their shared commitment to children and families was a powerful basis for collaboration.

\*Parents as Teachers is a parenting education program that was developed by the Texas Department of Mental Health.



*So after three years, we were cooking. We liked being together; we liked being in a room together; we had learned about each other's agencies; we were better professionals.*

Jeannie Heller

**If children and families are not being helped, learn to respond differently:** Jeannie believes, and the success of the Family Center has proved, that if services aren't helping children and families, professionals have to both look at what is getting in the way of consumers using the services and change the way that services are offered. The enthusiastic involvement of the community in the Family Center and the many positive changes in the lives of residents reflect the fact that "parents care deeply about their community and about their children." Professionals just have to learn to reach them in appropriate ways.

**Develop an interagency form to minimize paperwork for families and agencies and promote collaboration:** In order for agencies to work together effectively, they need to be able to communicate while respecting as much as possible the confidentiality of families. Recognizing this need, the Children's Partnership Board members determined to develop a universal intake/referral/release form which would allow them to share relevant information and prevent families from having to "give their names, addresses, social security numbers and the ages of their children fifty million times, as if they were new people each time they walked into an agency."

The agencies were asked to bring all of their forms to a meeting. A foot high stack of paper was created, which visibly demonstrated one of the barriers facing those who seek services and caused the group to consider, "My God, what are we doing to families?" It took months, but the members of the CPB were able to create a form\* which included the essential elements required by all of the agencies. This form is completed with the families, who assess their own needs, establish their own goals and sign their names to indicate their status as partners. The release form lists all of the CPB agencies and requests that families initial those which they will allow to share information about them. Although the consistent implementation of the new form by forty-five agencies has been a long struggle, CPB members acknowledge the importance of this step toward a more family-friendly system.

*You know, professionals talk about families and I've heard them say that the parents don't care, that families don't care, but I've just never seen it. I'm out at homes every single day, and I've never found it. So I began to take a novel approach: well, maybe the professionals aren't doing their job right.*

Jeannie Heller

\*For copies of the intake/release/referral form, please contact Project Unity.

**Integrate systems to reduce duplication of services:** When the Children's Partnership Board members began to meet together, they had an idea that some of the families were receiving duplicative services, but the need to respect families' confidentiality prevented an accurate assessment of the level of duplication. When the universal intake/referral/release form began to be implemented, the Children's Partnership Board members learned that some families were receiving eight or nine home visits a month from several agencies. Some children were receiving two or three developmental screenings in one month. These duplicative efforts were costly in terms of time and money, and were unlikely to either empower or help families. The new form allowed them to develop a system in which one agency became the priority agency for each family. The priority agency carries the master file, and takes primary responsibility for nurturing and working with the family. If another CPB member sees the family, a record goes back to the priority agency. This system has reduced duplication, speeded referrals and fostered accountability among agencies.

**Focus on family needs rather than agency functions:** When CPB agencies come together, Jeannie encourages them to leave their agencies, bureaucracies, forms and regulations behind. Then they can be free to look for ways to address the real needs of families without filtering them through preconceived ideas about professional and agency roles. This allows them to "see what we can do together as a group."

**Develop programs that respond holistically and flexibly to family-identified needs:** The Family Center is a structure through which families can be supported in whatever way they need to be supported. A comprehensive, holistic approach is used. All kinds of services are available, but on any given day the staff and the activities will be different. The building is not important. It's the concept that is important, a neutral place, a place to come for whatever you need.

#### E X A M P L E

*I thought we'd start out with forty-five or fifty kids. We have two hundred children a night! The neighborhood said it was a need. It works - it just works if you match what you do with what they feel is their priority.*

Jeannie Heller

Veronica and her three children had been on AFDC for many years, and experienced all of the stresses of the neighborhood. She says that because of her anxiety, "I threw up every day before the Family Center was here." The support and sense of belonging that Veronica found at the Family Center calmed her stomach and changed her life. Her relationship with the Family Center empowered her and allowed her to begin to experience her potential. She was chosen to fill the crossing guard position that the Community Voices activists won (see p. 80), and since then has attended classes at Blinn College and moved out of government housing into her own home.

**Develop community programs based on the needs identified by community members:** Project Unity held Town Meetings to ask residents of the highest crime neighborhood in Bryan what they wanted and needed. The families identified that their children needed access to recreational activities in the evenings and on weekends. "Our kids have nothing to do; they are hanging out in the streets." Consequently, one of the first services provided by the Family Center was

to plan family fun nights. The response from the neighborhood was overwhelming, and there are now two hundred children each Friday and Saturday night, playing games, watching movies and participating in such activities as a drill team and Girl Scouts. Food is provided by the Food Bank and volunteer help by students from Texas A&M.

#### E X A M P L E

A project that developed during family fun nights at the Family Center was a neighborhood quilt. One of the professionals from the prenatal clinic, who is a quilter, donated her time, and the neighborhood came every Friday night to work on a quilt. Everyone was enthusiastic not just about the product, which was beautiful, but about the friendships that developed, the networking and visiting that naturally occur when people are working together. For many of the participants, who had never undertaken anything like this, it was difficult to find the courage to put their first thread into the quilt. They were afraid that they would "mess up." But they created a work of art, of which they are justly proud. Soon their children's handprints will be added as the final touch, and the quilt will hang at the Family Center.

#### **Involve community members in the definition of a family-friendly system:**

Jeannie believes that too often professionals assume that they know what communities want. At town meetings, CPB members learned that families wanted a system that is family-centered, and where there is trust between citizens and agencies, and empowerment of neighborhoods. They wanted management shared between the professionals and community members and a system that recognized the dignity of all people. The Family Center has been so successful because it was based on this vision that came from the community.

**Bring services to where people are:** The Children's Partnership Board members realized that it's not enough to have a Family Center. For various reasons, many people cannot or will not go there to obtain services. So Project Unity purchased a van to become their mobile center. It has a fax machine, a copier and a laptop computer so that a team of professionals can work right out on the streets, away from their home office, yet have access to the information that they need.

*We go out one family at a time, one home at a time, visiting with our neighbors, just learning about families, introducing neighbor to neighbor, trying to help with the isolation issue.*

Jeannie Heller



Staffed by whichever members of the CPB are appropriate for the tasks of the day, the mobile unit goes to certain streets or homes to provide an individualized response to family needs, such as blood pressure checks, developmental screenings, or services for the blind, or to church or department store parking lots to respond to neighborhood needs, such as immunizations. An outreach person usually goes out first to talk to families, identify needs and let them know that the mobile unit will be coming. The Family Center program manager then assembles a team of the necessary professionals to discuss how to most effectively meet the needs that have been identified, who will take what role and where the funding will come from. The mobile center works because of its individualized services and interprofessional teams, but also because it is a neutral, non-threatening place. People want to come and see what is happening.

**Hear the voices of community members and take action:** Aware of the importance of hearing from the community, Project Unity began to hold town meetings to which neighborhood residents and people in power, such as the town manager and the school superintendent, were invited. At the first meeting, parents were very angry about conditions in their neighborhood, the cost to their children of these conditions and the perceived unresponsiveness of government leaders. Neighborhood residents felt that the problems they were having, such as crime, trash in the streets, deteriorating schools, and unrepaired water lines, should have been obvious to those in power. They had difficulty believing that the behavior of city officials would change because of what they had to say. The meeting was quiet at first, then heated up as community members vented years of frustration. City officials calmly listened and subsequent actions revealed that they had really heard the concerns of the community.

#### E X A M P L E

*I became deputized as a registrar at one of our CPB meetings, and I registered fifteen people to vote. It felt so wonderful because I was helping people to have their voices heard.*  
Jaslin Smith

For years residents had been asking for a crossing guard at a dangerous intersection. An elementary school child had been hit by a car there the previous year. A study of the intersection revealed that it did not meet the statistical requirements for a crossing guard, yet city officials recognized this as one of those situations where numbers do not tell the whole story. They also understood that there were unique circumstances in this neighborhood and that the crossing guard issue had symbolic importance to the community that went far beyond the real, practical need. When the school year began with a crossing guard in place, the neighborhood celebrated. They had been heard, and together they had accomplished something important.

**Bring community members together to advocate for themselves:** Also at the first town meeting, Project Unity staff invited volunteers to sign up for Community Voices, a fifteen week course on developing leadership in the community. Volunteers began meeting every Thursday night, focusing on neighborhood issues and developing strategies to find solutions. One very important concern for residents was that their children should have a school like the ones in more affluent areas. When a bond issue for a new school for the neighborhood



was on the ballot, Community Voices members became voter registrars and registered the neighborhood, encouraging them to vote for the bond issue. The bond issue passed, and now Community Voices members are on the committees that are helping to determine what kind of school will be built. In Jaslin's words, "People saw that we really took the time to voice our opinion on what's wrong and to suggest ways that problems could be solved." Community Voices members have also partnered with the city's Neighborhood Enhancement Action Team to address improving the appearance of the neighborhood. And in response to the need for youth activities, they have established a drill team, a baseball team, and a Girl Scout troop.



### **Assess needs continuously and with community**

**involvement:** Not content with town meetings as a method of identifying community priorities, Community Voices members have begun to go out into the neighborhoods. Through a concept called the Community Engagement Process\*, fifty community volunteers were trained to interview their neighbors to identify "what we already know," "what we need to know" and, after the interview process, "what we're going to do now that we know." Besides eliciting important information, this process has the benefit of nurturing neighborhood leaders by training and empowering them. And the face to face contacts with up to one thousand families are certain to increase the level of community awareness of the Family Center services and involvement in the change process.

**Support collaboration by building relationships:** Because of the level of trust and the shared vision that have developed out of the meetings of the CPB partners, working together in the Family Center and the mobile unit to meet the needs of families has become easy. Everyone knows what they are supposed to be doing. Responsibility is shared. If one agency or one professional cannot provide something, then the other can. Everybody just pitches in to create a holistic approach to families. Relationships are also such that when there are problems between agencies or professionals, open communication is the norm and issues are resolved.

### **Experience the benefits of collaboration for families and professionals:**

- **One collaborative effort leads to another:** A group called the Early Childhood Coalition† formed as a result of the CPB meetings. They enjoyed being together, saw the power of working together and found other ways to combine their efforts. Because members of this subgroup all had an interest

*I won't be the only one honking my horn about Martin Luther King Drive being torn up and we want something done about it. And we want abandoned houses to be torn down. It's going to be a group effort with the city and the residents. And we're going to keep it nice once we get it the way it needs to be.*

Jaslin Smith

\* The Community Engagement Process was developed by Philliber Research Associates, 28 Main Street, Accord, NY 12404. Phone: 914-626-2126.

† The Early Childhood Coalition members are: Bryan Head Start, MHMR Early Childhood Coalition, Bryan Independent School District Parent Education Partnership Program, Child Care Management Services, College Station Independent School District Head Start, Project Unity Family Center, and College Station Together as Parents as Teachers.





*And one thing that I have noticed with collaboration is that we're so comfortable with the agencies that we don't have a problem telling them when something isn't going right. We don't feel intimidated saying 'You need to pick up the ball because this family needs such and such.'*

Jaslin Smith

in parent education for families with children from birth to age five, they now co-plan two annual day-long parenting conferences, one in the fall and one in the spring. These conferences are the result of collaborative efforts that involve some CPB members, but also other agencies and groups that the Early Childhood Coalition have recruited for this project. All of the agencies cost share for child care, food, scholarships for families and transportation. Approximately one hundred seventy-five parents and children came to the last conference – a very successful training effort.

- **Collaboration benefits professionals:** Because collaboration works for families, it works for professionals. Everyone feels successful when the families they work with are feeling successful. In addition, the CPB provides its members with camaraderie and connection, the feeling that they are not alone. They feel support, that there are a whole lot of people out there wanting to help and strengthen families.

- **Collaboration transforms professionals:** Not being alone and feeling that they can make a difference is changing the way that professionals work. CPB members have reported that the feeling of cooperation and renewed commitment to families that they feel after being together has changed their behavior in other groups and in other situations. For example, members of the CPB passed the hat at a meeting to raise money to sponsor a baseball team that a housing project sorely wanted. They came up with \$300. Project Unity matched it, and there was a simple, immediate and generous solution to a neighborhood need. Another professional reported: "I left so inspired from the meeting. One of my young patients had miscarried and I hadn't gone to see her, and I thought, 'I just don't have the time to do it.' But I got to a red light, and remembered what George (a Community Voices member) had said about how we can't underestimate the potential of just one person to help another. I turned right around and went to see the teen."

- **Collaboration challenges stereotypes:** A recent CPB meeting, which was built around the "non-professional" community, brought volunteer and

church groups together with professionals to look at how to “wrap around” families as welfare reform changes their reality. Part of what participants learned was that some of the lay groups had stereotypes about professionals. They believed that professionals have all sorts of rules and guidelines and therefore aren’t there for people who need help. In contrast, “We, the church community, or we this volunteer organization, we help people in need.” The meeting made significant progress in broadening everyone’s perspective. The volunteer groups heard how grateful professionals are for their assistance. They also learned that professionals really do care about children and families and are often just as frustrated as volunteers with rules and barriers that are keeping them from meeting human needs.

- **Collaborative groups provide a neutral place for agencies that are involved in conflict:** Some turf issues often persist despite collaborative efforts. For example, in Bryan/College Station, there is heavy competition among the major health care providers. The health professionals who come to the CPB meetings are the front line staff who continue to work side-by-side with each other in the Family Center and the mobile center. As the Director of Project Unity, Jeannie strives to remain neutral. This allows her to bring the players together on specific projects, such as to develop a recent grant application to fund a position that would coordinate health care for all of the professions and agencies that work out of the Family Center. Such opportunities to work together affirm for the participants the importance of collaboration and may in time contribute to resolving the conflict.

## **PARTNERSHIP LESSONS: EDUCATION/TRAINING**

**Provide students of all professions with internships where they can learn about families from families:** Project Unity’s Family Center has internships for student nurses and teachers and is hoping to involve future physicians in Saturday clinics. These internships allow students to learn in a very real way what is happening to families in their homes and in their neighborhoods. The experience also enables them to learn very quickly about the forty-five different agencies that provide services out of the Family Center. They learn how these agencies can help them as professionals, and that all they have to do is call one agency to access all of them. Jeannie believes that teachers and other professionals will be more likely to become involved with the problems that children are experiencing if they know what to do about them.

**Develop opportunities for shared training to benefit professionals and the families they serve:** Part of every CPB meeting is a sharing of information about training opportunities so that agencies, professionals and families are aware of current training that might be helpful to them or to which they might be able to contribute. Also, the collaboration agreement that members sign commits them to participating in interprofessional development activities. Jeannie believes that there are areas of knowledge that should be common to all

*I am so passionate about this – that our future professionals, our teachers should do their internships with us before they go into the classroom...I really think that they can’t possibly know what to do with children until they understand the family dynamics that are happening today.*

Jeannie Heller

of the agencies and professions. An example is a training that she provided for CPB members on how to work with children and adults in poverty. This training asked them to examine their stereotypes and look at whether their preconceptions are getting in the way of their supporting healthy development for families. Such joint trainings promote the sense that professionals are working toward the same goals and share certain values and attitudes. Jeannie also believes that growth in the knowledge of its members must be an integral part of the growth of the collaborative.

With Project Unity in place, our community is changing. The people within the neighborhood are changing, are getting jobs, are buying a house, are getting out of government housing, or doing something that's real different. Magical things are happening.

Jeanne Heller



# Applying Lessons Learned: Family-Centered, Interprofessional Education and Practice

*by Bonnie Strickland, PhD*

One of the striking lessons of this publication is that we already know how to create programs and systems that work for children and families. The family-responsive, exemplary programs described here have demonstrated what families and professionals working in partnership can accomplish. Peanut Butter & Jelly's statistics show that in 95% of the families in their programs, domestic violence does not recur. And most of the children they serve remain with their families. That's incredible! I think the challenge is not to invent new ways to improve things. The problem is that we can adequately support certain families, at certain times, living in certain places, but we have not yet really grappled with the challenge of sustaining those benefits and expanding them so that they are available and beneficial to all children and all families living in all communities.

Outstanding programs are created and implemented by professionals who work from a family-centered, interprofessional perspective, and the examples in this publication demonstrate some of the qualities and practices of such professionals. Fundamentally, they are family-responsive and they understand the relationship between content and context in their work. One of the consistent messages from family members is, "The people whom we would welcome to work with our family are family-responsive, and by being family-responsive, they are culturally-responsive." These professionals understand families, because they pay attention to families. In addition, they realize the importance of this responsiveness. They know that how they work with families is every bit as important as the content that they bring from the perspectives of their individual disciplines.

**To be family-responsive, professionals must learn the critical skill of listening.** Maggie Schwarz, a social worker, said, "Push back the paper, put down the pen, and listen." I think all of us love the sound of that, and yet we are also

aware of the challenges that are involved in making it happen. Especially from a health perspective, with capitation rates and managed care keeping us closer and closer to billable hours, taking the time to listen is quite a challenge. Yet we're hearing families say, "We need it," and we're hearing professionals and providers say, "Listening is so important to us that despite all of the obstacles, we have figured out a way to do it." It is not acceptable to say, "We would, but we don't have time." We must recognize that hearing from families and gaining a broad understanding of what they want is just as important as any intervention that we might plan.

**Family-centered, interprofessionally-trained professionals recognize family members as good decision makers.** Maggie Schwarz said that families not only have the framework for this puzzle, they have most of the pieces. That's a very different paradigm from the one I grew up with, which was closer to, "As the professional, I have all the pieces and I may share a few with the family." Since professionals who work from Maggie's paradigm understand what families have to offer them, they will take the initiative to insure their full participation. Trish Thomas, the mother of a hearing-impaired child, said of her son's auditory/verbal therapist, "She just pulled me right into this partnership." Trish's wording is significant. This professional did not say, "Oh, here's an invitation to a meeting which has been scheduled without any regard to whether it's convenient for you, and which will be held with or without you." She said, "You're a partner, and I'm bringing you right into this partnership."

**A family-centered, interprofessionally-trained professional is flexible, just as families are flexible.** Successful programs and professionals are willing and able to adapt both what they do and how they do it based upon the understanding that they have gained through careful listening to the family. Unfortunately, the disciplinary structures that we create do not always support such an individualized approach. It seems that often the more specialized we get, the less flexible we become. However, families are saying, "My life changes from day to day and I need you to change along with me," and we professionals must find a way to respond to this clear message.

**Professionals who are trained in family-centered, interprofessional practice envision their roles as stretching beyond traditional disciplinary boundaries.** It is very important that we are good at what we do clinically or in the classroom, but an interprofessional perspective also demands that we learn some skills that are beyond our disciplinary training. One of these skills is advocacy. The word advocacy was used over and over again by the families and the programs in these pages. The fact is that in order to be effective practitioners, we have to be advocates, navigators and negotiators. We have to be service coordinators who somehow pull the pieces together. I think that most of us as professionals have a philosophical expectation that we will be advocates, but there is often a "disconnect" between intention and action. This incongruity may reflect the way we are trained. If I am a teacher, I am trained to teach. It is not my job to be concerned about what happens to my students after I leave at 3:10 or 3:15. And if I am concerned, I may not have the skills and knowledge I need to tap into

the needed resources. However, the voices in this publication are sending a different message: It is the responsibility of every professional to be an advocate and a leader in creating responsive, effective supports for the families with whom he/she works. We must teach our students to view their professional roles and responsibilities broadly, and give them the skills they need to be effective advocates for children and families.

**Family-centered, interprofessionally-trained professionals take a holistic approach and know how to involve others in their vision.** They operate from a perspective that says, "My job is more than your child's health, or your child's education, or your child's emotional well-being. My job is making sure, with others, that your family has the opportunity to live a satisfying life in the community. Whether the child has a disability, or is poor, or lives in a family where there is domestic violence, it is my job to be part of solving those problems." Working from that perspective, the interprofessionally-trained person also says, "I can't do my job without the rest of you, other professionals and community members." The message is not, "It would be nice if I could talk to the rest of you," but, "I simply can't do it without the rest of you." And it doesn't stop there. It goes a step further and says, "Since I need partners, I'm going to go out and find them." Pat Hackett-Waters, a mother of a young adult with special health needs, said, "The family knows the teacher, the family knows the physician, the family knows the social worker, the family knows the juvenile justice department, but these professionals don't know each other." The new paradigm would say, "I can't do my job without you and I'm going to find and involve every single one of you who are going to make it possible for me to do my job on behalf of this child and family."

It is very clear that family-centered practice and interprofessional approaches are not new. Polly Arango, whose son is twenty years old, said, "Right from the beginning there were people who understood, people who recognized our family's strengths, who knew they should involve me and that I could do good things for my son." Twenty years ago there were professionals who respected, nurtured and depended upon the expertise of families. And professionals and families have recognized for years the importance of a holistic, interdisciplinary approach. At a recent National Commission on Leadership in Interprofessional Education meeting, Tom Tonniges, a pediatrician, read the group an article written in 1977 by Rosalie Kane, a social worker. Her message was: "Teams are flourishing, teams in mental health, teams in health, teams in education... It's the way to go. Teamwork is what we need to do for families." This was written twenty years ago, so it is apparent that these are not new ideas. In one way that fact is discouraging because we have not managed to put these ideas into practice, sustain them and make them universal. But in another way it is encouraging because we know that we don't have to walk around in the dark. We have studied family-centered and interprofessional practice, and we have experience with implementing them. We do know some things that work.

The challenge, as I said in the beginning, is to sustain and expand exemplary practice, which means that in professional education, we have real work to do. I





think it's a survival challenge. I think that if we know what works for families, if the programs and families in this publication can teach us what works for families, then it is incumbent upon us to learn these lessons and to translate them into curriculum and into continuing education for professionals in the community. That means changing curriculum so that we teach professionals to understand the importance of the context and the "inter" part of professional, and so that we teach professionals to go out and find the partners that they need when they are working in communities. Preservice curricula and continuing education programs have to reflect these new values, skills and knowledge. We can't just leave it to chance. And then we have to hold ourselves accountable for making these changes, demonstrating their benefits and institutionalizing them in some way.

I think this is doable. I feel energized by the inspiring examples in this publication. I really feel that the families and the programs have given us some good concrete ideas on which to move forward, and that together we can create systems that will support and build upon the strengths of all families and all communities.

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# Responses and Recommendations for Practice

## Selected Lessons from Partnerships at Work

by Mary Skidmore Taylor, MSW

This section is a synthesis of the lessons learned from the successful programs described in *Partnerships at Work*. The purpose is to provide an overview of the ways in which these programs are translating family-centered, integrated, community-based and culturally competent approaches into practice.

### Lessons Learned: Practice with Communities

1. Ask families how they define their community and work with their definitions.
2. Work in partnership with community members on all activities.
3. Ask communities what they want and plan services around the priorities that community members identify.
4. Learn about the community from the community: the way power is structured, the challenges to cohesive action and the unique roles of culture, class and ethnicity.
5. Build partnerships among community members and health, social service and education systems:
  - a) Develop a common purpose/vision.
  - b) Build consensus by focusing on what families need rather than on agency functions.
  - c) Identify areas of conflict and work to resolve them.
  - d) Establish relationships through face-to-face interactions and nurture them through regular personal contact.
  - e) Establish a culture in which difference is valued and all voices are heard.

- f) Establish a culture in which the benefits of collaboration for families, professionals and agencies are regularly acknowledged and appreciated.
6. Plan systems that combine agencies' strengths to respond holistically to families' self-identified needs.
7. Create systems which reflect the cultural diversity of the community.
8. Simplify access to health, education and social work resources.
9. Support community members in coming together to advocate for themselves.
10. Develop a process that consistently identifies, strengthens and empowers community leaders.
11. Identify and nurture community strengths.
12. Assess needs continually with community members as partners.

### **Lessons Learned: Practice with Families**

1. Believe in families; they want what is best for their children and their communities.
2. Focus on families' strengths.
3. Understand the importance of cultural competence and make its development and enhancement an ongoing priority.
4. If children and families are not being helped, change the helping system.
5. Listen to families and understand their changing needs.
6. Create individualized plans to meet the individual needs of families.
7. Work from a flexible definition of family and include the whole family in programs and services.
8. Transcend professional roles to demonstrate commitment and caring to families.
9. If there are other professionals involved with a family, work with them; if a family wants a team, help them to create one.
10. Create a welcoming environment for families.
11. Create a respectful environment for families and staff.
12. Support community activities and encourage the participation of agency staff.
13. Work with youth, families and the community to assess, implement and evaluate programs.
14. Bring services to the community in ways which honor families' requests.
15. Value and promote continuity in staffing, which allows the development of accumulated wisdom and builds community trust in programs.
16. Make commitment to children and their families the foundation for all programs/activities.

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# Response to Partnerships at Work: A Family Perspective

by Betsy Anderson

The Family Connection, the March 1996 meeting of the National Commission on Leadership in Interprofessional Education which inspired this publication, was a powerful experience in watching parents, young adults, a grandparent, and professionals talk about their work together. The focus was always on how professionals can collaborate with children and families and with each other so that children and their families can lead real and meaningful lives together in their home communities.

In a variety of ways and words, the speakers' stories exemplified the elements of family-centered care (Shelton & Stepanek, 1994) which have helped to guide a movement toward more partnership between families and professionals. For example, the fifth element is:

*Recognizing and respecting different methods of coping and implementing comprehensive policies and programs that provide developmental, educational, emotional, environmental, and financial supports to meet the diverse needs of families.*

When Peanut Butter & Jelly works with a young mother with developmental disabilities to teach her, through modeling and the use of pictures, how to make formula for her baby, they are bringing this element to life. So are the members of the Children's Partnership Board (Project Unity) when they agree to put agency agendas aside to provide holistic services to families that are based on their individual strengths and needs.

When Project Unity takes its mobile center out into neighborhoods, "just learning about families, introducing neighbor to neighbor," and when Peanut Butter & Jelly sets aside time and space in their family centers for coffee and connection, they are practicing the sixth element of family-centered care:

*Encouraging and facilitating family-to-family support and networking.*

In a variety of ways and words, the speakers' stories also exemplified the principles of family/professional collaboration (Bishop, Woll & Arango, 1993). PACER's Team Training on Transition teaches teams of students, family members and professionals to work together to develop Individual Education Plans (IEPs) that are based on a student's own hopes and dreams and stated in terms of her/his goals, tasks and commitment. This is an example of a training that exemplifies the first principle of family/professional collaboration:

*Promotes a relationship in which family members and professionals work together to ensure the best services for the child and family.*

When Peanut Butter & Jelly staff take the time to practice "platica," to sit with a family and just get to know them, they are demonstrating the fifth principle:

*Creates an atmosphere in which the cultural traditions, values, and diversity of families are acknowledged and honored.*

Project Unity involves families (the Family Center), professionals (the Children's Partnership Board) and community members (Community Voices) in efforts to improve the quality of life in an urban neighborhood. In this way, they are modeling the seventh principle:

*Brings to the relationship the mutual commitment of families, professionals, and communities to meet the needs of children with special health needs and their families.*

What is striking about the programs and practices is that they are trailblazing. Each program is described either as a way to overcome currently inadequate programs and practices, or as an innovative way to address new and emerging issues. The late 1970s and 1980s have been a time of tremendous experimentation with new ideas and new ways of working. The family and professional collaborative examples in this book demonstrate that it is indeed possible to provide services and resources using new practice paradigms. These programs and practices are successfully addressing the real needs of children and families.

So what does this success mean for us now? What does it mean for children and families? For professionals? For communities? How can we transmit what we know and have learned to individual families and to local community programs? And how can this knowledge and experience be used to improve the care of our own children? Funds from a variety of federal and state programs in the areas of health, education, and social services have been spent to demonstrate creative new ways to serve children and families. Our highest priority must be to see that the successful models that have been developed are put into practice more universally for all families.

Here are some of the important areas for families to address in our efforts to integrate models of high quality practice into the universal, everyday experiences of all children and families:

- Professions, by their very nature, have a body of knowledge and a way to transmit it to new young professionals in training, both those at the preprofessional level and those seeking continuing development. As families, we really need to develop mechanisms and opportunities that assist us in transmitting our particular body of knowledge to professionals and to new parents in a consistent manner.
- Although many family leaders have frequent contact with professionals, and speak or participate in pre- and in-service training for professionals, we need to have a more purposeful and comprehensive approach to professional training by families.
- We also need to have ongoing, collaborative relationships between family members and professionals that just naturally (or very purposefully) exist at all points and places in our systems of care. Some examples are: family memberships on advisory committees, parent/family members employed in various settings, such as state health departments, and ongoing information sharing and discussion between families and professionals.

Let us, together, continue to think about methods to transmit what families and family leaders know to individual families who are new to the system, to new and continuing professionals who may have either just taken their first job, or recently changed jobs, and to the systems within which professionals work. Let us also think about mechanisms for communication that will ensure that there is ongoing and two-way information exchange between families and family leaders and professionals. If we agree, as the model programs in this publication demonstrate, that successful practice requires the participation of families as partners, then we must continue to spread this message far and wide and to develop the means for making these partnerships a reality.



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See appendix (p.130–131) for full listing of the key elements of family-centered care and the principles of family/professional collaboration.

**Betsy Anderson** is Project Director of the Partners in Communication program at the Federation For Children with Special Needs, Boston, Massachusetts. She is the mother of three children, one of whom is now a young adult who has special health needs. Ms. Anderson has been a nationally recognized parent leader in providing training and consultation to professionals and mentoring to parents and families.



# **Response to Partnerships at Work: A Social Work Perspective**

*by Paula Allen-Meares, PhD*

## **Introduction: Professional Value Systems**

Social work, like other professions, has a unique value system which underlies educational preparation and professional practice. We operate within this value system whether our understanding of it is explicit or implicit. As I reviewed the ideas and examples contained in this publication, it struck me that in their totality they reinforce the core values of the profession of social work, which include respect for individual viewpoints and backgrounds and an appreciation of the importance of holistic and collaborative approaches.

## **Valuing Diversity and Individual Needs**

In order to value diversity, we need to recognize that each human being has his or her own worth and dignity, right to self-realization, and potential. Through this recognition, we learn to value individuals for their singularity and to see the individual strengths – and weaknesses – we each possess. Valuing diversity “signifies that participants have different but equally valuable contributions.” (Allen-Meares, Washington & Welsh, 1996).

Our nation has long championed the cause of individuality – at least in theory – but we have been quicker to label variation in the family structure as abnormality. Just as we value single human beings for their individuality, we can recognize and value diversity in social institutions like families. Families have the same rights as individuals: to be respected, to be viewed as unique and different, and to be supported/empowered so that they achieve their maximum potential.

The papers in this publication make apparent that successful social work practice depends on perceiving the uniqueness of each individual and family and on viewing each family as possessing particular strengths. Social workers who are employed in a variety of organizational settings (including hospitals, child and family agencies, mental health settings, and schools) are keenly aware of the essential role that families play in maximizing their children's potential throughout the developmental stages (infancy, early childhood, middle childhood and adolescence). Social work practice includes helping families to use their strengths and to become the best possible advocates for their children; in effect, as Hooper-Briar and Lawson (1994) argue, social workers need to help families to recognize their strengths and their power to use them on behalf of their children:

Empowerment is founded upon accessing new resources, identifying new action domains, and reclaiming rights. It is aimed at creating new capacities for families to act for themselves and to gain increasing strength and a sense of control over their lives... (p. 23)

Family Voices reminds us that each family is unique, with its own history, values and ways of behaving, and that families are indeed the experts on the lives of their children. Although this notion of “individual as unique” is fundamental to

social work education, contact with large numbers of families can lead practitioners to overlook it. The Gallivan-Hackett-Waters family and Peanut Butter & Jelly contributions underscore the importance of social workers' maintaining their cultural sensitivity and embracing a flexible definition of family.

In order to appreciate the variety of individual strengths and perspectives of individuals and families, social workers must carefully listen and respond to the voices of both their clients and their collaborators. The contributors for the PACER Center remind us that we must listen to families in order to understand that their needs are not static. As family needs evolve, so must we allow ourselves to be transformed as a consequence of our interaction with them. Effective problem solving requires that we be flexible and creative and not tied to traditional visions and roles. As Hooper-Briar and Lawson (1994) remind us, "Collaboration is an inventive process," and we need to invent solutions as situations unfold (p.15).

The listening process includes assessment, a fundamental aspect of social work practice. Assessment takes into account the particularity of individual situations; it requires a careful analysis of both the challenges the child faces and the strengths of all involved. Unfortunately, practitioners may conduct an initial assessment but fail to engage in the ongoing assessment required to meet the changing needs of families. Heller and Smith's contributions remind us that social workers must continually ask children and families what they want and need in order to ensure that the services they are providing are appropriate and family-responsive.

### **The Collaborative Approach**

I have been arguing that social work practice values diversity among individuals, families, and, by extension, social work and health professionals. But how are we to value difference and still work together in the child's and family's best interests? The answer is not to compartmentalize the child's needs or to perform specific tasks in isolation from the others who are involved in the child's well-being. Instead, we can put our individual strengths to best use by working together in teams of professionals and other concerned individuals; as Allen-Meares, Washington & Welsh (1996) note, "The higher the level of collaboration, the greater the strength the group will have for collective action and commitment to the goals" (p. 258).

Interprofessional collaboration should not be the domain of a professional group; as the voices in this publication suggest, children and families are best served by everyone concerned working together. Heller and Smith point out that collaboration is founded upon a continuing relationship and a common purpose, in this case the child's well-being. Professionals are not the only collaborators; as Jeannie Heller of Project Unity reminds us, families are crucial partners in col-



laboration. Families contribute to the collaborative effort through their unique perspective and knowledge, and they provide us with a history of coping with difficult struggles in innovative ways. They are indeed the linchpin to other informal and formal systems of support.

Our role as professionals ought to include supporting family participation and encouraging and empowering the family voice amongst the sometimes overpowering voices of professionals. Families are partners in the promotion of change and empowering them has direct consequences for the well-being of their children today, as well as for preventing problems in the future. Bishop, Woll & Arango (1993) summarize the relationship dynamics as follows:

Families and professionals bring essential knowledge, skills, and experience to a collaborative relationship. In the past, families were often considered receivers of professional expertise, without acknowledgment of the unique and valuable contribution they make. The collaborative model recognizes the expertise of all the people involved in caring for the child... (p. 20).

Linking home, school and community into a single system of caring for children reinforces the rightful role of families as equal partners in a collaboration in the children's best interests.

### **Collaboration and the Ecological Perspective**

Collaborative approaches to problems and issues involving children are based on the notion that individuals and institutions are inevitably interrelated, that nothing exists in isolation from its environment. This notion is a principle fundamental to the ecological perspective, a theory that has become increasingly popular in social work research, practice and literature. This perspective highlights the transactions and interactions occurring naturally between the child and various systems and/or institutions (e.g., school, home, and community). Ecological theory is thus a theory of interaction and/or transactions; it deals with the broad, complex reciprocal transactions between organisms and their environments (see Allen-Meares, et.al., 1996). In a situation involving a child, the environment is defined as the aggregate of external factors/conditions that affect the child and his/her developmental outcome. Since the family plays a critical role in determining developmental outcome, families must be viewed as equal partners in collaborations aimed at advancing the child's well-being.

### **Community Involvement**

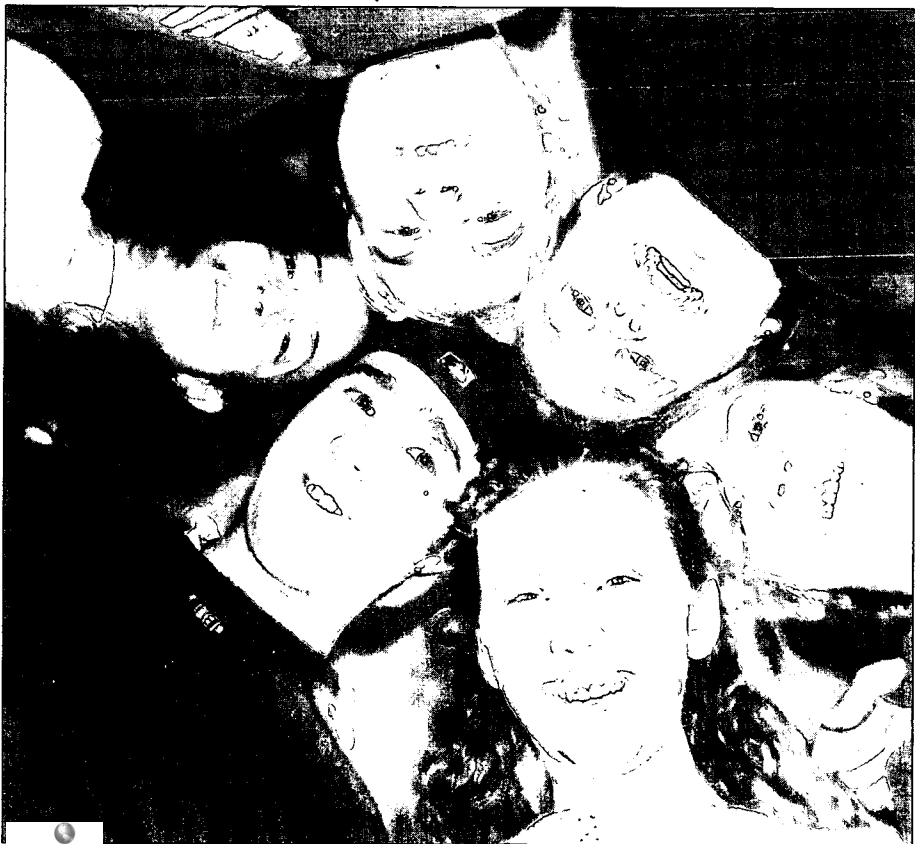
An ecological perspective provides the holistic view that Family Voices suggests is a prerequisite for the delivery of high-quality services. Although a holistic view includes an appreciation of the significance of communities as the context within which families live, grow and learn, Bishop, Woll & Arango (1993) have argued that their potential has been too often ignored:

While a great deal of attention has been paid to the need for and importance of a commitment from families and professionals to children... there has been less focus on the need for a commitment from communities (p. 35).

Social workers have traditionally helped link individuals with environmental/community resources. This role is congruent with the ecological perspective and its emphasis on building support systems to enhance individual functioning within environments such as the community. Social workers are trained both to engage the community as a resource and to support and strengthen that resource. Communities can make invaluable contributions to collaborative processes, and at the same time derive substantial benefits from their participation in these processes.

**Conclusion: Implications for Educational Preparation of Social Work Practitioners**

As the papers in this publication suggest, social work practice is based on recognizing that the diversity of individuals, families and professionals means there can be no single Band-Aid approach to the issues facing families and children today. Since different individuals need different solutions, children often need an interdisciplinary team of professionals, relatives and community members to work together to help them to maximize their potential. The need for a family/child-centered collaborative model of practice holds important implications for the educational preparation of social workers. The current pre-service educational programs for social work often do not sufficiently integrate other professional groups and families as collaborators into the knowledge base. This situation is not unique to the profession of social work; other professional groups (e.g., teachers, doctors, school nurses, special educators, and educational administrators) are also educated in isolation both from one another and from the real-



ities of daily practice. Social work educators thus can profoundly influence the future practice of social work by teaching students the interactive, collaborative process this publication applauds. We can ensure that our teaching represents children, family members and communities as active collaborators in remediation and prevention, rather than as passive recipients of services. We can show our students the successes of collaborative team approaches, and we can model integrated social work practice by including in our curricula paradigms which suggest partnerships with professionals from other fields. If our students are trained in these processes now, they will be better prepared to address the needs of children and families in the future. If the educational preparation of other professionals similarly reflects the need for collaboration, children will be more likely to benefit from a team of dedicated professionals prepared to work together to help them address their individual needs through a holistic perspective.

### A Final Note

Since family-centered, community-based, holistic approaches are embedded in the social work tradition, and advocacy is an essential social work skill, social workers are uniquely positioned to provide leadership to efforts to transform our system of services for children and families. The ideas and examples in this publication can help us to evaluate our own practice. They can also guide our interactions with other professionals and with the communities within which we live and work. Our professional commitment to children and families demands that we actively engage with others in efforts to solve the complex problems which are now facing families and communities. The voices in this publication reinforce both the urgency of the task and the hopefulness with which we can approach it.

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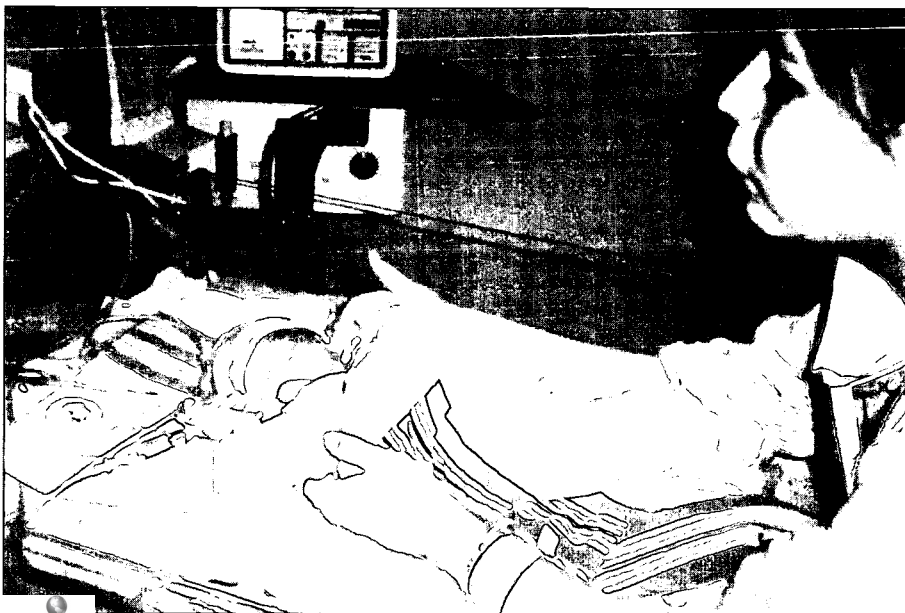
# Response to Partnerships at Work: Health Professionals' Perspectives

by Tom Tonniges, MD and Dianne Haas, PhD, RN

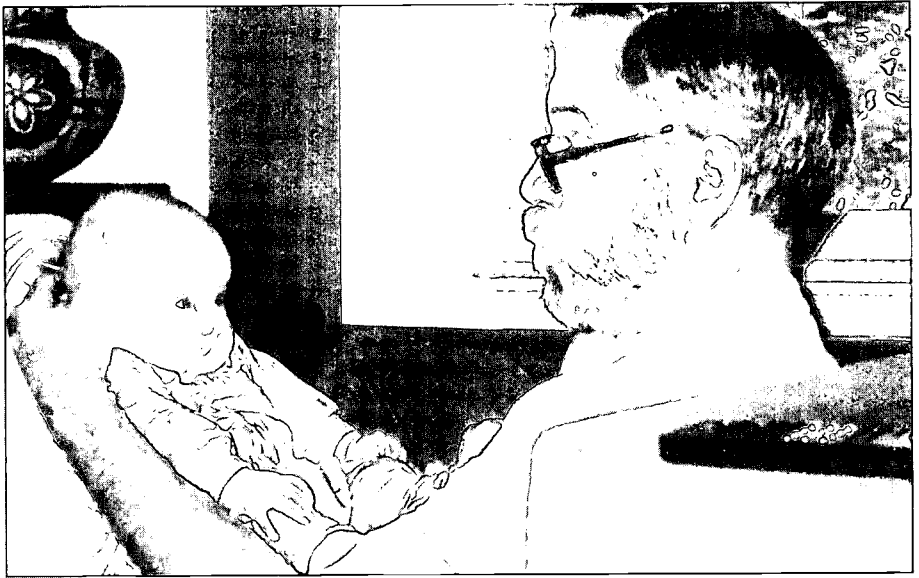
During the past thirty years there has been a significant change in how families view the health professional and how the health professional views the family. Beginning in the 1970's, technological advancements and other developments increased the distance between the child and family and the health professional. The basic needs of the child and family were often dwarfed by the complexity of the health care system. It wasn't uncommon for the family to have to interact with ten, fifteen, even twenty different and unrelated health care professionals instead of one health care team. However in the 1990's, with the development of the concept of *family-centered care* in the context of a *medical home*, the idea of partnerships between families and health care professionals is shaping a different reality.

Family-centered care implies that the family is at the center of the health care delivery system and is in equal partnership with physicians in determining the course of the care they receive. Family-centered care is an essential element of the medical home concept. The American Academy of Pediatrics defines the medical home as care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally competent.

Is the medical home concept and its emphasis on the importance of family/professional partnerships new to families and health care professionals? Yes and no. Have health care professionals been educated in this concept? No. Have individual health care professionals and families practiced this concept? Yes. As the influence for health care decisions moves from the primary care physician, to the institution, to the family, all members of the health care team will need to rec-







ognize the importance of partnership if they are to succeed in the future. Managed care will expect it; families will demand it.

In this publication, families and professionals from a variety of communities tell stories about how to make partnerships work. Though many different stories are told, similar themes repeat themselves – maximization, constancy, expertise, and collaboration. These themes play a key role in how health care professionals and families can work together to achieve optimal outcomes for children with special health care needs.

### **Maximization**

Maximization is defined as the greatest quantity, upper limit, largest number. For the health care professional working in partnership, it means advocating for supporting the child and family to reach their maximum potential. It means giving them the opportunities afforded all children and families. It has been said that to treat all equally, each needs to be treated differently, according to his or her special needs. This is so true if we are to partner with the child and family. It means giving that extra amount of time, making that extra call and going that extra mile, side-by-side with the family – not out in front or behind them.

Glen Gallivan and his family provided clear examples of how he and others have maximized his life. Although he could not play sports, he could join in the process by being the team statistician and coach. His mother and grandmother's *just do it* attitude, encouraging risk-taking, benefitted not only themselves, but many others with whom they had contact.

As health care professionals, we have been trained to do it one way. Frequently, our attitudes, beliefs and behaviors have kept us from embracing maximization. Managed care and families, however, expect us to question how things have been done in the past. Now, more than ever, we must listen closely to what our patients and families tell us. And when we do so, we will find that

there are many positive outcomes. How many major breakthroughs have already been made that have been the result of the health care professional listening to the patient and family? For example, twenty years ago no one would have predicted the impact that home health care has had on the medical system. But today, because of a mutual trust between the health care professional and the family, many services are delivered in the home with the direction and input of the family.

To actively promote maximization, we as health care professionals will need to step out of our boxes and begin to see the world as the child and family frequently see it. By doing so, we will find that the world of the child with special health needs and his/her family may have a few more detours and bumps, but it is the same world that we all see.

As each of the presenters told his/her story, a challenge was given to all health care professionals – maximize health and minimize disability and disease. The successful partner in the future will build on strengths. The shift to a strengths perspective can be very challenging for health care professionals who come from a traditional deficit model, but it is a shift that we must make. Consider the child with a reading disability. Such a child may have difficulty learning to read, yet he or she has many other skills and talents that make him/her unique as an individual. It is this uniqueness that is the great equalizer among all of us. Often we forget to look beyond the deficits of a child to see his/her glowing qualities. We need to be reminded of the positive qualities that distinguish the child from his/her peers – be it his beautiful smile or her upbeat sense of humor. The next time we are in a room full of professionals at an Individual Education Plan (IEP) meeting, why not ask everyone to identify a strength of the child whose life is being discussed? In that way, the team will have a more thorough perspective of the child, one that takes into account not only limitations but also maximum potential.

By focusing on the importance of teamwork, we all can have a significant impact on maximizing the potential of the child and family. A good analogy is the use of a recipe to make a good dish for dinner. Individually, all of the ingredients have a solitary taste. It is only when these ingredients are mixed together that you have a delicious combination of flavors. This is how professionals should view partnerships with families and with each other. By working together toward health promotion and maximization of the whole child, the health professional can provide services to the whole person, not just treat the disease.

As health care professionals, we bring many strengths to the partnership model. Health care professionals have a developmental perspective, which helps us to understand normal variation. We also bring the concept of the differential diagnosis. Together these perspectives allow us to promote the concept that *one size does not fit all*, that each child and family have unique strengths.

Through teamwork and collaboration, health care professionals can assist those with special health care needs to focus on their inherent strengths and unique qualities so that, as Glen Gallivan said, we all can be productive members of our society, thus helping all of us to maximize the world we live in.

### ***How can health care professionals utilize the concept of maximization in their practice?***

- Work with subspecialists to provide home care so the family and child can lead a more normal life.
- Work with your local United Way Allocation Committee to make sure that the needs of families are identified and gaps are filled to provide needed services.
- Advocate with families so their children can participate in school activities.
- Attend Individual Family Service Plan and IEP meetings and help the teams to focus on the child's and family's strengths, rather than on just their acute needs.

### **Constancy**

People need constancy. Constancy means steadfast or faithful, not varying, continually recurring. Parents and family members are certainly steadfast and faithful; they are the constant and continual presence in their child's life. However, no parent can be with a child twenty-four hours a day, seven days a week, nor would that be optimal for children and families. Families need ongoing support in the care of their children. And professionals need to be available when the family needs them, not just during the Monday to Friday, 9:00 a.m. to 5:00 p.m. hours.



The child and family can and should expect constancy within the health care system. Yet with managed care, including Medicaid managed care, taking an increasing share of the health care financing for children, this is being challenged. Everyone would agree that constancy is important, but with plans limiting subspecialty care, and frequently managing cost rather than care, the family's needs can get lost. One way that constancy can be preserved is by families, health care professionals, and third party payers buying into the concept of the *medical home*. This home is not made out of bricks and mortar, but rather a commitment that does provide constancy. The medical home concept implies that support is given to the child and family throughout their lives or for a significant period of time. It means the provision of continuous care that does not change as the child moves through the educational system. It supports the development of and access to all of the services that families need. It works with other health professionals to make sure that the family gets the most needed services.

### ***What can health care professionals do to promote constancy for children and families?***

- Make sure that the concepts of the medical home are part of the mantra of the primary health care professional.
- Have input into the school board and its policies to ensure that the concept of constancy is part of every policy decision.
- Work with managed care organizations to make sure that their policies and procedures do not undermine the concept of constancy, e.g., by paying for care in the emergency room but not for similar care in the medical home.

### **Expertise**

To be an expert is to acquire a skill. This can be done by education, training and practice. As health care professionals, we have had plenty of opportunity to develop our expertise. A theme of this publication is that families too have expertise that must be recognized.

When parents tell their pediatrician that they feel their child cannot hear, the pediatrician needs to heed the expertise of those parents. It is well known that the parent is the expert in this situation. Far too many times the health care professional has ignored parents' concerns, only to find out months and years later that they were right, and the child really was hearing-impaired.

Parents are indeed the experts on their children. They know the history of their children even before they were born. Parents know the intricacies of their children's behavior, when they are sick and when they are not. They understand subtle changes and pick up on improvement in physical signs long before the health care professional can. They are the first to note a change in muscle tone following an increase in medication or following a change in the frequency of physical therapy. So why is it that health care professionals do not always listen to the family?

The health care professional has spent years learning about disease and how to treat disease. However, the health care professional, in general, has not been taught that the family has something specific to contribute. It is families who know, or with support and understanding can come to know, what they need. It is families who are ultimately accountable and responsible for the well-being of their children. It is families who must make decisions about the resources they require and what they can afford in relation to their child with special needs and the entire family system.

Families are the experts in defining the needs of their members. Honest, open and forthright communication about what each partner brings to the situation will facilitate a growing circle of expertise. The task at hand, as demonstrated by the contributors to this publication, is to bring together the collective expertise of all those involved. As professionals partner with families and each other, their

expertise grows, as does their appreciation for what the child and family can contribute. The circle of expertise will be greatly expanded as we move toward more shared learning with the family.

***What can health care professionals and families do to promote their expertise?***

- Parents can share with their health care professionals new medical advances that they have learned from other families.
- Families can be connected to state and national organizations that promote knowledge about their child's disability.
- Professionals can participate in and encourage the development of educational opportunities through their local, state and national professional organizations.
- Health care professionals can hire the parent of a child with special health care needs to provide on-line information about the needs of families.

**Collaboration**

The word collaborate means to work jointly with others; help the enemy. One might say that there are no enemies among us, because we share a common goal, but indeed sometimes we are our own worst enemies. As each discipline of the health care field has evolved, we have become increasingly specialized, and we have also become increasingly separated from those who have specialties different from our own. Our expertise has been developed with good intent, but in ways which often cause the multiple disciplines that are attempting to provide care and support to families of children with special health care needs to be at odds with one another, and with the very families that they serve.

A continuous message provided in each of the examples in this publication was to include children and their families in the decision making process and to collaborate. Perhaps it is the families who understand collaboration the best. They are the ones who have provided leadership and example by forging collaborative relationships with their professional colleagues through organizations such as the Association for the Care of Children's Health, Family Voices, the Institute for Family-Centered Care and Parent to Parent organizations.

It is because of the professional and parent leaders throughout the country that progress has been made and family/professional collaboration has evolved to the current significant level. As families have organized and increased their presence, so has their influence grown. Physicians, nurses and social workers have been partners in care for centuries, which gives them a unique responsibility and opportunity to lead others in developing best practices in collaboration.

Working collaboratively with and for families will provide greater opportunities for children, leading to better developmental gains, less time dealing with

the health care system, and more time in the community, school and home with family and friends.

***How can health care professionals promote collaboration in their practice and in the community?***

- Make sure that there are links from the practice to the greater community by such means as hiring a social worker to facilitate this linkage.
- Hire a parent of a child with special health care needs to keep you in touch with the realities in the community.
- Help the community to conduct a comprehensive needs assessment. This will identify gaps in services and set the stage for a collaborative effort to meet the unmet needs of families.

**Conclusion**

The health care professional and the family are at a unique time in history. Now, twenty years after landmark legislation, families of children with special health care needs are recognized for being what they have always been—the center. Health care professionals must establish partnerships with children and families and with each other, by being available on an ongoing basis, using their expertise and working collaboratively. In this way, we will successfully promote the maximum well-being of children and families and be part of the movement advocated in this publication toward a system of services that is compassionate, comprehensive, coordinated and culturally competent.

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# Response to Partnerships at Work: An Education Perspective

by Dean Corrigan, EdD

My response highlights the ideas expressed by families that I believe have the most far-reaching consequences for the professions responsible for improving the delivery of education, health and social services. The degree to which these ideas are considered will determine the success or failure of new integrated service systems and the interprofessional training programs to implement them.

1. Families must be at the center of any system designed to serve them. Families are the connecting link across the professions as well as the connecting link between service providers and other families needing assistance.
2. If families are expected to implement a plan, they must be involved in developing the plan.
3. An integrated services program cannot be transplanted from one setting to another; it must emerge from the cultural setting in which it will operate.
4. No matter how expert professionals are, they cannot do things *to* and *for* others. The role of the service provider is to help to create the conditions for change – to enable families to act on their own behalf.
5. Families have little difficulty describing the essential characteristics of the most effective service providers they have known. Descriptors like enabler, facilitator, catalyst, navigator, and orchestrator are frequently used by parents, and they say a lot.
6. The message from one of the parent panelists, “If people can’t learn the way you teach, then maybe you had better teach the way they learn,” applies to all of the helping professions, because all helping professionals are educators.
7. Priorities in the future must turn from treatment to prevention. Education equals prevention and families are the first teachers.
8. Education is more than schooling. It must start at birth and extend throughout life, as they say in Vermont, “from conception to kaput.” Education takes place in a wide variety of places and involves people of all ages.
9. Families can be resources for improving training programs as well as service delivery systems. Who knows better what problems children and families face in the places where they live, learn and work? Who knows better what good services to solve these problems look like? Who knows better what knowledge, skills and values effective service providers possess?

## Cultivating Optimism

Lessons learned from the best practices described in this publication have great significance for practitioners, trainers and policy makers. Perhaps the greatest obstacle to progress could be viewed as “learned helplessness” on the part of service providers as well as clients. When the rug gets pulled out from under peo-

ple, when hopes are dashed time after time, ordinary human beings give up. Going to meetings where nothing happens is worse than doing nothing. Service providers get captured by their calendars and the bureaucracy. Over time they develop a subtle allegiance to maintaining the status quo; they stop seeing the potential in themselves, families and systems of services. "We've tried that before," becomes just one of a long list of good reasons for avoiding change.

In contrast, families like the Hackett-Gallivan-Waters family, who have personally faced the greatest challenges, present and demonstrate a strong case that the cultivation of optimism must replace the spiral toward futility. Their message is to build on a strengths model, not a deficits model. A shared vision of the future is what will bring families and service providers together. Developing this vision and the programs to implement it will take trust and confidence. It will take organizations where everyone feels a pervasive caring for others, and it will take authentic leaders. Leadership is not viewed here as synonymous with administration. Leadership emerges at every level, in families and in community agencies.

Perhaps the most fundamental impetus for family/interprofessional education and practice comes from a recognition of the integrity of individuals. Such integrity makes people more than the sum of professional perspectives.

### Interprofessional Collaboration

Both families and service providers seem to agree that interprofessional collaboration enables professionals to realize their own wholeness through interaction with other professionals, and to offer a holistic response to persons who seek their help. Interprofessional collaboration also helps each profession to recognize the important resources that other professionals can bring to their concerns and endeavors. Turf battles are eliminated by the recognition that it would be preposterous for any human service professional to address today's complex problems alone. Problems are too multifaceted for any professional to tackle single-handedly. Also, collaboration can remind service providers of the benefits of engaging their clients in partnerships.

### Changing Professions and Agencies, Not Just Coordinating Them

Probably the most significant realization for all those involved is that interprofessional collaboration does not mean just coordinating the institutions and agencies as they function presently. If that is all that happens, interprofessional collaboration will have accomplished very little. We must expect that each of the parts of the system will be improved by the interaction among families, agencies and professions. For example, I believe that there is great potential for collaborative practice to change school policies on corporal punishment, which is still legally sanctioned in twenty-four states.



One of the reasons I am so committed to interprofessional collaboration is that I believe that interaction with other professions from the perspective of the “whole” child will cause teachers and principals to reexamine not only corporal punishment but other outmoded practices that disregard the health, safety and human development of children. The histories of professions show that they change from external as well as internal forces. When the hitting of children or other harmful practices are discussed in interprofessional teams that are concerned with the care and development of the “whole” child, in groups that include pediatricians and social workers in addition to teachers and principals, I believe the dialogue and resulting action will be different.

### **Changing Substance, Not Just Structure**

The family-centered and consumer-driven strategies described in this volume change everything, including the use of school facilities and scheduling. Activities for families are expanded during the school hours as well as after school hours. The four programs described in this publication all showed how the roles of school principals, teachers, school psychologists, social workers, health care providers and community developers are recast when services become family-centered.

Furthermore, after reflecting on the comments of the Family Voices members, I believe that the biggest changes are going to take place around issues of substance, not just structure and strategy. The changes in schools called for by parents involved in integrated service systems go much deeper than changing the form of schools. Fundamental purposes of education and programs change when schools become family-friendly support environments. In the programs presented in this publication, the strategies of family empowerment and community development produced comprehensive changes involving many community partners. The family-centered, community-based approach involves nothing short of the reimagining and reinventing of schools and community agencies, and their relationships with one another.

### **Simultaneous Reform**

In the past, my perspective on simultaneous reform focused on reforming programs of preparation in universities while at the same time reforming practice in schools and community agencies. I expressed my belief that changing one could not be done without changing the other, because practitioners need training before they can be expected to implement new approaches. Passing mandates and new laws is not enough to change professional practice.

After reviewing the ideas of Polly Arango and the Family Voices members in this publication, I now see the need for another area of simultaneous reform. Policies must be developed and political action undertaken to foster interprofessional and interagency collaboration. Instead of single issue categorical legislation and the funding of “projects,” new comprehensive legislation must be developed that considers together the functions of all of the agencies and professions serving children and families. Politicians who make their reputations by writing legislation in the areas of education, health, and social services must be invited into the same room to write legislation that facilitates linkages across programs and

funding streams for the creation of comprehensive, family-centered, community-based systems rather than disconnected categorical projects.

To be successful in this political arena, interprofessionally oriented leaders must possess knowledge of policies affecting integrated services and interprofessional preparation. They must also learn the political strategies necessary to implement and influence these policies in the future. They must be tough-minded. They must realize that everything important is political, just as everything important is controversial. If it isn't important, adversaries will let you stay busy on it forever.

Advocates who want to place "children first" must expect opposition and be ready to respond to it together. Viewed as partners, the education, health and social service professions constitute the largest work force in the nation. If all of these partners, and the families with whom they interact, were to start moving in a long wide line toward the politicians and policy makers who can make a difference, they could accomplish whatever they set out to do. The potential of such a coalition to influence the various forces that develop policies and programs designed to serve children is unequalled.

Concern for children and families must be the central purpose for reforming the system; it must be the value base that runs the engine, and provides motivation over the long haul, especially when the going gets rough. The most vivid truth of this new age is that this country's future will be determined by the actions of those citizens and professionals who are motivated by a bonding of affection and caring for others, especially the nation's children. The human service professions must be the enablers for this group of Americans.

The education, health and social service professions have a common stake that they must accept and profess to others. This publication can be used as a guidebook on ways to involve families as partners in improving integrated service systems and improving interprofessional training programs. And it can be used as a clear, jointly expressed rallying call to place the future of children and families where it belongs, at the top of America's agenda.

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# National Commission on Leadership in Interprofessional Education

The National Commission on Leadership in Interprofessional Education (NCLIE) was created to study ways to produce a new generation of interprofessionally oriented leaders in health, social work, education and other human service professions whose members possess the knowledge, skills and values needed to create new community service systems for children and their families. Sponsored by the Association of Teacher Educators (ATE) during its first three years (1993-96), and supported with grant funds from the Maternal and Child Health Bureau (MCHB)(1993-1998) to provide leadership in interprofessional education and practice to the professions of social work, medicine, nursing, and education, the Commission is guided by the groundbreaking document, *Principles To Link By* (U.S. Department of Health and Human Services, 1994) and collaborates with a variety of professional associations through its fifty-five (55) members. The basic criterion for membership on the NCLIE is active involvement as a policy maker, practitioner, trainer or family partner in the implementation and evaluation of integrated services and interprofessional education.

The Commission developed and ratified the following purpose statement:

*"Through a family/professional partnership, the Commission will support the preparation of a new generation of interprofessionally oriented leaders in health, education, and social work, who possess the knowledge, skills and values to practice in new community-based integrated service delivery systems.*

*"The National Commission will focus on interprofessional preparation in both preservice and continued professional development. The best community based practices with children and families will serve as knowledge bases by which changes are made in university missions and programs." (1995).*

The three MCH-funded Interprofessional Development Grants which provide leadership and support to the Commission are:

## Partnerships For Change

Family/interprofessional collaborative practice is one of the approaches that is integral to high quality services for children and families. The overall goal of Partnerships For Change (PFC) is to improve services to children with special health care needs and their families by focusing on integrating this approach into the education and practice of professionals.

PFC's efforts to bring an interprofessional focus to university-based programs began in social work with the inclusion of knowledge, skills and values about interprofessional practice as required competencies for students in field placements. Qualitative interviews with field instructors and student journaling about interprofessional learning provided data to inform PFC products while at the same time contributing to the visibility of the new focus both at the University of Vermont (UVM) and in the community. As interprofessional practice became an interest for students, faculty increasingly requested that PFC provide resources for teaching interprofessional content and included these resources in policy and practice classes. PFC's yearly seminars for students, faculty and field instructors have also distributed resources and supported the continued development of interprofessional learning strategies. Like other project activities, focus groups with students from different disciplines served a dual role, supplying data for PFC products while bringing information about interprofessional practice to other

academic departments, such as physical therapy, nursing, education, pediatrics and speech and language. PFC also developed and has begun to test a peer consultation model for the interprofessional education of students from different disciplines who are placed in community settings. Education-related products include resources such as a teaching module on interprofessional practice and suggested wording for required competencies in interprofessional practice and policy for students.

PFC is conducting qualitative research with children with special health needs, their families and the professionals with whom they work in order to describe the role of interprofessional practice and coordination in providing services that are responsive to families' priorities. Data is being analyzed on an ongoing basis and results have been and will continue to be presented in workshops which employ diagrams of families' perceptions of complex service systems as dramatic, visual evidence of the importance of interprofessional practice. PFC has also collected descriptions of programs which demonstrate high quality, family-centered interprofessional practice and conducted related qualitative interviews. The result is the dissemination of recommendations and strategies which can be found in such products as *Information Exchange* bulletins and the book; *Partnerships at Work*, which highlight promising community practice.

PFC's partners in the development and dissemination of family/interprofessional collaborative education and practice approaches include: children, young adults, parents, and extended family; Federal MCHB, Division of Services for Children with Special Health Care Needs; Family Voices; NCLIE; the Council on Social Work Education; the National Association of Social Workers; the American Academy of Pediatrics; the National Coalition on Family Leadership; the Association of Teacher Educators; VT Department of Health, VT Interdisciplinary Leadership Education for Health Professionals (VT-ILEHP), Parent to Parent of Vermont; UVM students and faculty in the departments of social work, education, physical therapy, speech and language, nursing and medicine; elementary, middle and high schools; and community agencies.

Publications available include: MSW Field Education Manual, Revision (Cass, 1995) which includes required interprofessional experiences; *Interprofessional Education and Practice: A Selected Bibliography* published by the Council on Social Work Education and a developing bibliography on family authored and family/professional co-authored literature; *PFC Information Exchange* bulletins; *Partnerships at Work: Lessons Learned from Programs and Practices of Families, Professionals and Communities*; a monograph, *Family/Professional Collaboration for Children with Special Health Needs and their Families*; position papers; and training resources.

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## **Higher Education Curricula for Integrated Service Providers**

The overall goal of the Oregon project, Higher Education Curricula for Integrated Service Providers, is to assist selected colleges and universities to develop offerings that will cross-train their students from various disciplines so that upon graduation they can effect integrated services at the local level. The first phase of the project was identifying family-centered, community-based projects across the country that have been successful in applying an integrated service approach that benefits at-risk families, children, and youth. This phase is complete, and a report is available. Three academic sites, California State University Fresno, the University of New Mexico, and the University of Southern California have been selected to develop curricula and create training programs for integrated services. Publications available include: two annotated bibliographies on resources for integrated services; bi-annual newsletter, *Service Bridges*; a set of six training modules from California State University Fresno; and periodic reports on project work.

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## **Health and Education Collaboration Project**

The Health and Education Collaboration (HEC) Project was created to identify, develop, and promote key aspects of collaborative interprofessional practice for training. The community-based Healthy and Ready to Learn Center (HRTL)) is the primary training and program development site for the HEC Project. HRTL provides direct services to families with children (prenatal to age five) who are at environmental risk. These services include prenatal and postpartum care, routine well-child care, child development information, parent-child activities, supportive counseling, and referral services.

HEC staff are responsible for ongoing HRTL staff development to assure that Center services are provided within the context of family-centered interprofessional collaboration. Thus the two programs work hand-in-hand to assure that families have access to an array of services that are delivered in a caring and coordinated manner.

Now in its third year, HEC has achieved three goals: 1) established HRTL staff as trainers at the Center (in addition to their roles as providers of services); 2) made HEC/University community-based training experiences more meaningful to the participants; and 3) promoted training in state and national initiatives whose goal was to improve children's school success by fostering working relationships among families and health, social services, and educational professionals. Available publications include two monographs, *Building Bridges: Lessons Learned in Interprofessional Collaboration, Year 1* (1995) and *Year 2* (1996).

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# **The Family Connection: Family and Interprofessional Partnerships**

March 29, 1996  
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# Principles of Family/Professional Collaboration

## Family/professional collaboration:

- 1) promotes a relationship in which family members and professionals work together to ensure the best services for the child and the family;
- 2) recognizes and respects the knowledge, skills and experience that families and professionals bring to the relationship;
- 3) acknowledges that the development of trust is an integral part of a collaborative relationship;
- 4) facilitates open communication so that families and professionals feel free to express themselves;
- 5) creates an atmosphere in which the cultural traditions, values, and diversity of families are acknowledged and honored;
- 6) recognizes that negotiation is essential in a collaborative relationship; and
- 7) brings to the relationship the mutual commitment of families, professionals, and communities to meet the needs of children with special health needs and their families.

## SOURCE:

Bishop, K. K., Woll, J., & Arango, P. (1993). *Family/professional collaboration for children with special health needs and their families*. Burlington, VT: University of Vermont, Department of Social Work, Family/Professional Collaboration Project. (Available from Partnerships For Change, University of Vermont, 228 Waterman, Burlington, VT, 05405-0160, (802)656-8800)

## **The Key Elements of Family-Centered Care**

- 1) Incorporating into policy and practice the recognition that the family is the constant in a child's life, while the service systems and support personnel within those systems fluctuate.
- 2) Facilitating family/professional collaboration at all levels of hospital, home, and community care: care of an individual child; program development, implementation, evaluation, and evolution; and, policy formation.
- 3) Exchanging complete and unbiased information between families and professionals in a supportive manner at all times.
- 4) Incorporating into policy and practice the recognition and honoring of cultural diversity, strengths, and individuality within and across all families, including ethnic, racial, spiritual, social, economic, educational, and geographic diversity.
- 5) Recognizing and respecting different methods of coping and implementing comprehensive policies and programs that provide developmental, educational, emotional, environmental, and financial supports to meet the diverse needs of families.
- 6) Encouraging and facilitating family-to-family support and networking.
- 7) Ensuring that hospital, home, and community service and support systems for children needing specialized health and developmental care and their families are flexible, accessible, and comprehensive in responding to diverse family-identified needs.
- 8) Appreciating families as families and children as children, recognizing that they possess a wide range of strengths, concerns, emotions, and aspirations beyond their need for specialized health and developmental services and support.

### **SOURCE:**

Shelton, T.L. & Stepanek, J.S.(1994). *Family-centered care for children needing specialized health and developmental services*. Bethesda, MD: Association for the Care of Children's Health. (Available from ACCH, 7910 Woodmont Avenue, Suite 300, Bethesda, Maryland 20814, (301)654-6549)

## **Fundamentals of Cultural Competence:**

Honoring the racial, cultural, ethnic, religious, and socioeconomic diversity of families by:

- 1) Recognizing the power and influence of culture in shaping values, beliefs, and experiences.
- 2) Understanding one's own cultural values, beliefs, and behaviors, and how one responds to individuals whose values and beliefs differ from one's own.
- 3) Learning about the cultural norms of the communities with which one engages, and about the extent to which individual families share those norms.
- 4) Approaching each family on its own terms, with no judgments or preconceptions, and enabling each family to define its own needs.
- 5) Helping families learn about how the mainstream culture is reflected in the service system, so that they are able to use the system to meet their needs.
- 6) Acknowledging that many families have experienced racism and other forms of discrimination that affect future interactions with service providers.
- 7) Eliminating institutional policies and practices that, deliberately or inadvertently, exclude families from services because of their race, ethnicity, beliefs, or practices.
- 8) Building on the strengths and resources of each child, family, community, and neighborhood.

### **SOURCE:**

The National Maternal & Child Health Resource Center on Cultural Competency for Children with Special Health Care Needs and Their Families, 1100 West 49th St., Austin, TX 78756, (800)434-4453.

# Project Unity

The following are lists of the members of the Children's Partnership Board and the InterAgency Coalition, collaborative groups which, with Community Voices and the Family Center, comprise Project Unity. The Children's Partnership Board members are direct service providers and InterAgency Coalition members are administrators from the agencies that staff the Family Center or otherwise support Project Unity's programs.

## Children's Partnership Board Members

Bryan Independent School District Special Services  
Brazos County Community Council  
Brazos County Health Department  
Brazos County Juvenile Probation  
Brazos Food Bank, Inc.  
Brazos Valley Interfaith Outreach  
Brazos Valley Rehabilitation Center  
Brazos Pre-Natal Clinic  
Bryan Adult Learning Center  
Bryan Community Policing  
Brazos Valley Community Action Agency-AIDS Services  
Brazos Valley Community Action Agency - Community Oriented Primary Care  
Brazos Valley Community Action Agency - Family Health Clinic  
Brazos Valley Community Action Agency - Family Health Psychological Services  
Brazos Valley Community Action Agency - Head Start  
Brazos Valley Community Action Agency - WIC  
Brazos Valley Development Council County Indigent Health Care  
Brazos Valley HealthSmart Coalition - Childhood Education Immunization Initiative  
Brazos Valley Workforce Development Board  
Child Care Management Services  
City of Bryan - Youth Services  
College Station Independent School District Head Start  
College Station Independent School District Special Services  
College Station Independent School District TAPS (Together as Parents)  
College Station Police Department  
Columbia Medical Center  
Department of Protective & Regulatory Services  
Early Childhood Intervention  
Family Outreach  
Health For All, Inc.  
Hospice Brazos Valley  
Lincoln Recreation Center  
Mental Health Mental Retardation Association of the Brazos Valley  
Options for Young Parents  
Parent Education Partnership Program  
Pathfinders - State Advisory Board  
Pathfinders - North Bryan Lions Club  
Project Unity Family Center Location  
Scott & White Pediatric Education Center  
Sheltering Arms  
St. Joseph Regional Health Center  
St. Thomas Aquinas Catholic Church

St. Vincent de Paul Society  
Texas Commission for the Blind  
Texas Department of Human Services  
Texas Department of Health  
Twin City Mission - The Bridge  
Twin City Mission - Phoebe's Home  
Windsor Pointe Apartments

### **InterAgency Coalition Members**

Ms. Alberta Anderson, Center for Human Development  
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Dr. Gary Badger, Scott & White Clinic  
Ms. Carol Barrett, Junior League of Bryan/College Station, Inc.  
Ms. Laurie Bell, Columbia Medical Center  
Dr. Bill Birdwell, BISD School Board  
Mr. Kermit Black, A&M Center for Housing and Urban Development  
Mr. John Blackburn, Director of Community Services, City of Bryan  
Ms. Amy Blevins, Interfaith Outreach  
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Dr. Michael Duffy, Professor, TAMU Department of Educational Administration  
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Ms. Suzy Griswold, Brazos Valley HealthSmart Coalition  
Fr. Sam Hose, St. Thomas Aquinas Catholic Church  
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